Priced out:

ending the financial penalty of disability by 2020

Scope

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Acknowledgements

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Foreword

Life often costs more if you are disabled. From higher transport costs to get to work, to the cost of an electric wheelchair; from higher energy costs, to a lack of access to affordable home contents insurance, disabled people face extra costs in most areas of their lives.

When we talk about improving living standards in the UK, we often think of economic growth, prices and wages. But what is rarely recognised is a problem that affects disabled people's living standards that pre-dates the recession – one owing to the additional costs of disability.

Disabled people currently pay a financial penalty on life.

This penalty has been recognised by successive governments since the introduction of the Mobility Allowance in 1975.[1] Yet the support disabled people get to help cover these extra costs is getting smaller and harder to access.[2] Approaches to tackling the root causes of these extra costs have been fragmented, and imbalances in the market mean that the costs of some of the things disabled people have to buy – for example, assistive technology – remain higher than they need be. Sometimes disabled people are forced to pay more for products and services – for example travel insurance – just because they are disabled.

Because of this penalty disabled people find it harder to enjoy family life fully, participate and contribute to their local communities, live independently, access education and training opportunities, find and stay in employment, build their own financial resilience and contribute to pensions.

With a General Election rapidly approaching, and with signs of economic growth in the UK beginning to show, there is an opportunity for political parties to set out what they will do to end this financial penalty.

Richard

Richard Hawkes
Chief Executive, Scope

Executive summary

Scope's 'Better Living, higher standards: improving the lives of disabled people by 2020' was the first in a series of reports that look in depth at the challenges within disabled people's living standards.

This report, the second in the series, argues that the extra costs disabled people face is the first important challenge. It brings together new research and analysis to give a fuller picture of extra costs. It includes data gathered through a survey and in-depth interviews, as well as an investigation into the disability wealth penalty conducted by the Centre for Analysis of Social Exclusion (CASE).

We recommend a multi-faceted approach to tackling the problem of extra costs. The Government must protect the budget for extra costs payments by taking them out of the cap on Annually Managed Expenditure (AME). It must make sure those who need support to help meet extra costs get it. It must make sure these payments keep up with disabled people's costs by placing a 'triple lock' on them like the Government have done on pensions, and tackle the root causes of extra costs by rebalancing markets and introducing cross-governmental accountability. This will ensure that there is fair, inclusive growth which does not leave disabled people behind.

1. Financial wellbeing and extra costs

Disabled people face many barriers in securing financial stability. Despite being ready and willing to work, they are more likely to be unemployed and underemployed. When in work, disabled people are more likely to be in lower paid jobs. On top of this, disabled people have to pay more to achieve a decent standard of living – spending on average £550 a month on disability related expenses.

2. The role of extra costs payments in maintaining living standards

Disability Living Allowance (DLA) and Personal Independence Payment (PIP) are crucial for disabled people to lead independent lives, to take up opportunities, increase their own income and contribute to their communities. But recent and planned welfare reform threatens these important payments. PIP assessments do not ensure those who need support get it, and the planned cap on AME threatens the budget for DLA and PIP.

Recommendation

Protect extra costs payments within the cap on Annually Managed Expenditure.

Recommendation

Redesign PIP assessments to more accurately identify disabled people's extra costs.

3. Extra costs payments do not go far enough

Some of the things disabled people must purchase are very expensive and currently DLA and PIP do not cover all extra costs. Therefore disabled people are still more likely to be in debt and unable to build savings.

As people in the UK are living longer it becomes a policy imperative that all people of working age are financially resilient and able to save and contribute to pensions. But as long as the income of disabled people is absorbed into the extra costs of disability, they cannot invest it into pensions or savings accounts and consequently enter retirement with little or no pension wealth.[3]

Recommendation

'Triple lock' DLA and PIP.

This would reduce the amount the Government save through DLA reform by only £45 million in the first year parliament.

4. Tackling the drivers of extra costs

Where extra costs can be driven down, they ought to be. Responsibility for tackling the problem of extra costs currently sits with the Department for Work and Pensions (DWP). Yet the root causes of extra costs arise in policy areas that are the remit of other Government departments. Due to market imbalances, some things disabled people have to buy are more expensive than they need be.

Recommendation

Ensure truly cross-departmental policy-making to identify and drive down the root causes of extra costs.

In 2014 Scope will be running a Commission into Extra Costs to examine ways in which the key drivers of extra costs can be driven down through rebalancing markets.

What are DLA and PIP?

DLA and its successor PIP contribute towards the extra costs of being disabled. They are non-means tested and non-contributory, meaning they can be claimed both in and out of work. Disabled people have control over how they spend these payments to cover the extra costs they face as a result of their disability. In 2014/15 there will be around 1.85 million working age DLA and PIP claimants[4] receiving between £21.15 and £138.05 a week.

Key findings

Disabled people pay on average £550 per month on extra costs related to their disability.

These extra costs can be:

- Products and services needed by disabled people and not needed by non-disabled people. For example disabled people spend on average £60 a month on food or drink for special diets or allergies and around £85 a month on specialist equipment[5]
- Products and services needed by both disabled people and non-disabled people, but that disabled people sometimes need more of, such as the cost of taxis to get to work when there is no accessible transport
- Products and services needed by both disabled people and non-disabled people, but that cost more for disabled people. For example one in five of disabled people feel they pay more for insurance generally because of their impairment[6]

As a result of these extra costs, disabled people:

- Are twice as likely to have unsecured debt totalling more than half of their household income[7]
- Are three times more likely to use door step loans[8]
- Have on average £108,000 fewer savings and assets than non-disabled people[9]
- In the 55-64 age group, the gap in the mean level of private pension wealth is £125,000[10]

1. Financial wellbeing and extra costs

Living standards are about whether you get a good education, have opportunities to work, whether you get to see friends, or can take part in family life.

Financial stability is crucial to everyone's living standards. Having enough income to cover the costs encountered in life means that you can avoid debt and can build savings. In turn, savings can be used for education and training, to relocate for a new job, to put down a deposit on a house, or to put aside for later life to ensure security and independence in retirement.

Financial wellbeing is a human right, as stated by the United Nations Convention for the Rights of Disabled People. Article 28 outlines disabled people's right to assistance with disability-related expenses and to an adequate standard of living including the continuous improvement of living conditions. Article 20 specifies that disabled people should have mobility at affordable cost.

Yet disabled people face many barriers to achieving financial security. Nine in 10 disabled people are in work or have worked in the past,[11] and more than one third (37 per cent) of disabled people who are not in work would like to work.[12] But currently only around one in two (49 per cent) are in work, compared to three quarters (78 per cent) of non-disabled people.[13] When in work, disabled people are more likely to be in lower paid jobs – on average disabled people earn over £1 an hour less than non-disabled people.[14]

In addition, disabled people often need to pay more to live their lives and contribute to society and the economy, facing extra costs relating to disability. The rest of this section will explore this financial penalty disabled people face.

What are the extra costs that disabled people face?

Extra costs are unique for each person but broadly fall into three main categories.[15]

Products and services needed by disabled people and not needed by non-disabled people. These can be one-off expenses, for example the initial cost of a wheelchair; or of home adaptations. Or they can be recurrent, for example the price of medicines; maintaining a wheelchair through replacement parts and batteries; covering the cost of a sign language interpreter; paying for therapeutic treatments to manage conditions; or buying special foods required for certain conditions.

"I have benefited from massage and physiotherapy but I had to pay privately for this using my savings and DLA." Katie (Living standards survey, Scope)

New analysis of research conducted by Demos shows that disabled people who responded to a survey were spending on average £60 a month on food or drink for special diets or allergies and around £85 a month on specialist equipment.[16]

Products and services needed by both disabled people and non-disabled people, but that disabled people sometimes need more of. These can be one-off expenses, for example buying a larger house to store medical equipment. Or they can be recurrent, such as paying for taxis more often to get to work when there is no accessible transport; replacing clothes more regularly because they wear out due to wheelchair use; using more energy to run more regular baths, or to keep the home warmer to ease the impact of certain conditions; or paying for more help around the home. Analysis of the Demos data shows that respondents were spending on average around £64 a month on household tasks.[17]

"My circulation is very poor. I get frostbite during cold weather, so I need to keep the house warm. And heating is very expensive. I wear a suit to work every day and constantly have to change suits because I have to carry everything about on my lap. So you can imagine it rubs away and my shoes get scraped when I try to transfer. So you're constantly going through. And I would imagine most disabled folk are the same. You know you just go through a lot more stuff." Bill, 57, Edinburgh (Living standards interview, Scope)

Some disabled people may need to buy more expensive ready-prepared meals, because their home has a kitchen that does not suit their needs, or for when they are recovering from a period of sickness.[18]

Many disabled people need more space to live in because of their disability. For example someone with spina bifida who needs a specially adapted bed may be unable to share a bedroom with their partner. The 'removal of the spare room subsidy' manifests as another extra cost for those who need additional space. 100,000 disabled people who will be hit by the policy live in specially adapted homes,[19] and there is a lack of appropriately

disabled people spend **£550 a month** on costs directly associated with their disability

sized alternative accessible housing available for them to downsize to.[20] Those affected by this policy will either lose £14 a week or be pushed into inappropriately sized, inaccessible housing.

Products and services needed by both disabled people and non-disabled people, but that cost more for disabled people. This can be because disabled people have no choice but to go to certain, specific providers for example for specialist clothing.

But it can also be because disabled people are unjustifiably perceived as being higher risk in the marketplace. For example, disabled people often pay substantially more to access financial product and services. Disabled people face large supplements for travel insurance based on their condition. Even those who have recovered from a medical condition still have to declare this to a travel insurer.[21] One in five of disabled people feel they pay more for insurance generally because of their impairment.[22] Six in 10 disabled people that Scope spoke to who had been turned down for insurance said it was because of their disability or condition.[23]

A recent report by Middlesbrough Council showed that some firms could be breaching discrimination laws by refusing to accept disabled passengers, or charging disabled people up to double fares for the same journey.[24]

How much do disabled people pay in extra costs?

Research by Demos shows that on average, **disabled people spend £550 a month on costs directly associated with their disability.**[25] One in 10 spends over £1,000 per month on costs related to their disability. Figure 1 shows the amount disabled people spend on disability-related costs each month, by proportion of survey respondents.

Another way to measure extra costs is to look at their impact on people's wealth. Extra costs mean that disabled people are left with a smaller share of their income that they can save or invest; lower wealth among disabled people is likely to reflect the long term effect of these extra costs. Statistical analysis of the Wealth and Asset Survey shows that **disabled people, on average, have £108,000 fewer household savings and assets than non-disabled people.**[27] This is even after we take into account other factors which could be driving the difference such as the fact that disabled people have, on average, lower educational qualifications, lower socio-economic status and lower 'earning potential'.

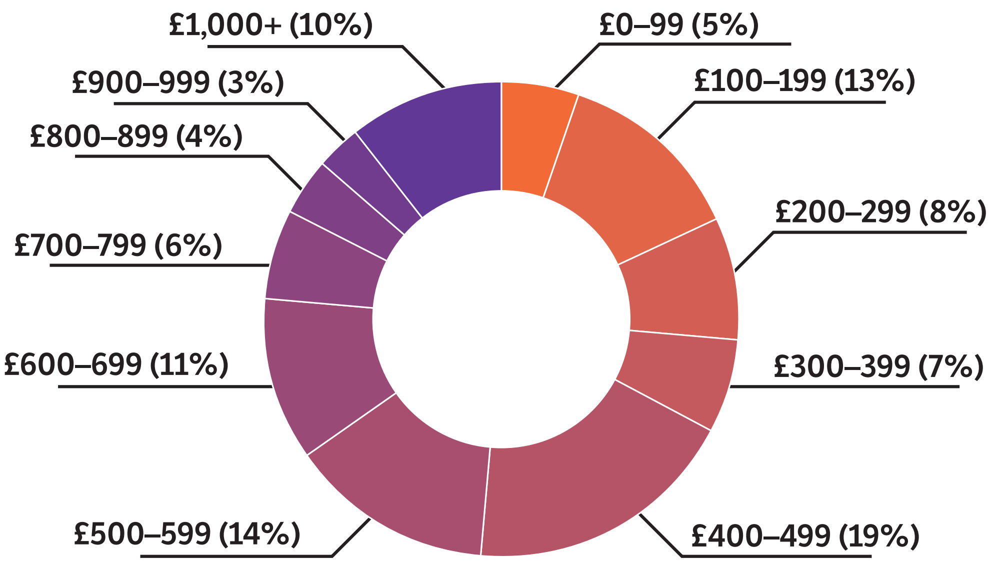

Figure 1: The amount disabled people spend on disability-related costs each month, by proportion of survey respondents[26]

2. The role of extra costs payments in raising living standards

Chapter one explored the evidence for the financial penalty that disabled people pay. In 1971, a Conservative government recognised that they should play a role in removing some of the financial penalty with the introduction of Attendance Allowance. This was extended by a Labour government in 1975 with the introduction of Mobility Allowance (MA). Currently DLA and PIP are payments intended to help contribute towards these extra costs (see box on page five for more details of these payments). This chapter sets out in more detail the role that extra costs payments play in supporting disabled people's living standards and the importance of protecting these payments.

Extra costs payments are about covering costs rather than replacing income

DLA and PIP are intended to go to those who face the greatest extra costs, rather than those with lower incomes. They are therefore different to the majority of the UK's welfare system which should act as a safety net for the people within it. It mainly exists to support people financially when they are excluded from the labour market due to illness or a shortage of jobs (Employment Support Allowance [ESA] and Job Seeker's Allowance [JSA]); when they are over retirement age (pensions); to supplement people's income when wages are inadequate (tax credits); or to change people's behaviour and incentivise people back into work (a central aim of Universal Credit's taper feature).

In recognition that extra costs payments are not income replacements or boosters, the payments are non-means tested meaning your income is not taken into account when your eligibility for the payment is assessed. There are many advantages to not means-testing – it reduces the administration costs associated with a benefit[28] and minimises disincentives to work that may exist elsewhere in the social security system (if a disabled person moves into employment they will not lose their DLA or PIP). It also means that the payment continues to go to those who face the greatest financial penalties, rather than to those with lower incomes.

Extra costs payments play a crucial role in maintaining disabled people's living standards

DLA and PIP are a necessity of life for many disabled people, regardless of their employment status, or whether they are at crisis point in their lives. They are equalisers –providing financial support to offset the extra costs that disabled people incur over and above those experienced by non-disabled people. They are about levelling the playing field and enabling independence so that disabled people have an equal chance to contribute to and benefit from economic growth, access services and participate fully in their communities. For example having a Motability car, paid for using the higher rate mobility element of DLA, enabled 16 per cent of under 24 years old to undertake a formal course which leads to a qualification, and 10 per cent to undertake informal learning. Currently there are 54, 500 working age DLA recipients in full-time or part-time education.[29]

Extra costs payments and employment

DLA is also crucial in enabling disabled people to work and maintain contact with the labour market.[30]

"Getting DLA has enabled me to work as I can buy necessary essentials to work as an equal. I am very worried when my DLA is reassessed as PIP that I will lose this vital assistance." Rhona, Leicester (Living standards survey, Scope)

386,000 (21 per cent) DLA claimants are in work,[31] and 36,990 (2.7 per cent) Job Seekers Allowance claimants who are actively seeking work claim DLA.[32] A survey of over 1,000 disabled people conducted by the Disability Benefits Consortium has found that over half of DLA claimants in work said they would not be able to work without it.[33] If this was reflected across the whole disabled adult population, this would mean that nearly 200,000 people need DLA to get to work.[34]

"I use my DLA to meet the extra costs of food that I can't cook and to pay for using a car to get to work. I don't know how I will cope if I lose it at the introduction of PIP." Elane, London (Living standards survey, Scope)

A study of the economic and social impacts of the Motability scheme estimated that it enabled 12,500 customers and informal carers to get a job and 56,100 to keep an existing job. This was estimated to be worth £1.2 billion in gross wages per year.[35]

"I am also extremely worried about changes to DLA because if I lose my Motability car, I don't see how I will be able to maintain work. I will not be able to afford to get me and my wheelchair to work each day." Jamie, Dunbar, 40 (Living standards survey, Scope)

21% of Disability Living Allowance claimants are **in work**

Over half of those DLA claimants in work said they **would not be able to work without it**

"Since losing 60 per cent of my DLA award I have lost most of my independence and also my Motability vehicle. This caused me to be unable to continue being self-employed and I have not had any support in returning to work." Leah, London (Living standards survey, Scope)

The proposed cap on social security spending threatens extra costs payments

The Government has made an explicit effort to protect extra costs payments from the impact of the benefit uprating Bill and the introduction of the £26,000 Benefit cap. Yet the proposed AME cap now threatens the very same payments.

Annually Managed Expenditure (AME) is Government spending that needs to be flexible.[36]
It covers things like social security payments, debt interest, and spending by local authorities. The Government currently controls the social security elements of AME spending through changing the generosity of, and eligiblity for payments, for example through the reform of DLA.

In the Budget 2014, the Chancellor announced that, starting in 2015 – 16 an overall limit of £119.5 billion will be placed on parts of social security spending. The cap will cover almost all social security elements of AME. DLA and PIP are planned to be within the cap and are at risk of being cut because of it.[37]

A breach of the cap will trigger a debate and vote in the House of Commons. After that it is likely that ministers may be compelled to make policy decisions to bring down social security spending.

DLA and PIP are non-means tested so do not respond to unemployment rates. Spending on them is unlikely to rise if the economy falters. Future demographic changes, and the expected drop in DLA recipients due to DLA reform,[38] are reflected in OBR forecasts upon which the level of the AME cap has been based.[39] It is therefore unlikely that spending on DLA and PIP will lead to a breach of the cap.

Perversely, though, the overall budget for DLA and PIP is threatened by its inclusion in a cap alongside other elements of social security that do respond to the economy, like Housing Benefit and Tax Credit. If the economy takes a downward turn, ministers bound by the cap may be forced to pitch extra costs payments against these more volatile elements in their decisions to bring social security spending in line with OBR forecasts.

In addition, the fact that the cap applies to year-long time periods, means it is likely to lead to short-sighted short-term cuts, such as differently up-rating benefits which is an easy way to guarantee a reduction in spending.

Recommendation

Protect extra costs payments within the cap on Annually Managed Expenditure.

Extra costs payments play a crucial role in securing disabled people's living standards and they must be protected from the potentially negative effects of a cap on AME. Spending should not be determined in any other way than offering support to those who need it, when they need it.

Therefore, the Government must protect extra costs payments such as DLA and PIP by taking them out of the cap or ring-fencing them within it. A ring-fence will mean that although the payments disabled people get will remain within the cap, in the case of a breach they will not be cut because the cost of other payments shoots up.

Recommendation

Redesign PIP assessments to more accurately identify disabled people's extra costs.

Recent reform of DLA has failed to recognise the social and economic benefits of extra costs payments. DLA is being replaced by PIP. The Government announced their intention to save 20 per cent of the budget through

reforms. Therefore the reform was not rooted in making sure that disabled people who need financial support to offset the extra costs of disability receive it. From April 2013, PIP claimants have faced tighter eligibility criteria, and will undergo regular face-to-face assessments. The Department for Work and Pensions (DWP) estimates show that 600,000 disabled people will drop out of the system by 2017, losing between £21 to £134.40 a week by 2013/14 rates.[40]

"I am afraid of losing DLA when I move to PIP, and I will become trapped in my home as I can't walk far without pain and use my DLA to pay for a car." Annabel, 54, Manchester (Living standards survey, Scope)

DLA assessments are heavily centred on the medical model of disability[41] and therefore do not accurately measure the extra costs people face. Analysis of Demos survey data shows that in all but two areas of disability-related spending there was almost no relationship between the level of DLA received and the level of spending.[42] The new PIP assessments (rolled out nationally in June 2013), which measure a person's inability to carry out certain tasks, will perpetuate this problem.[43]

A crucial part of the Government improving disabled people's living standards is to make sure that those who need support get it. The next Government should commit to replacing the current assessment of extra costs with a new assessment based around the following principles.

Six principles for a new PIP assessment

1. Co-designed and co-produced

Disabled people should be directly involved in designing and setting the new assessment criteria.

The only way the Government can ensure the criteria reflect the reality of disabled people's lives is to fully involve disabled people in setting the direction and principles of assessment criteria.

2. Multi-dimensional criteria

The assessment should reflect the fact that the barriers disabled people face, which result in extra costs, are multi-dimensional.

During the reform of DLA, Scope and 27 other charities called for the PIP assessment to better reflect the social model of disability, and the highly differentiated costs each disabled person faces.[44] Rebecca told us that the main thing that would improve her financial situation,

> **"Would definitely be getting the DLA back and having them realise that it's not just the fact that you can't walk so much. They need to learn to take into account everything… they seem to treat everything separately. But it's not; it's the cumulative effect of everything. Which ends up leaving you not able to do anything."**
> Rebecca, 44, Rochford (Living standards interview, Scope)

To reflect the multi-dimensional drivers of extra costs, the assessment should combine both a scoring approach and a semi-structured interview format, so as to ensure that the assessor gains as good an understanding as possible of the barriers that prevent the disabled person from living the full and independent life they value. Disabled people must lead their own assessment of the extra costs they face. This more nuanced, multi-dimensional approach might result in new components, different to PIP's current two – mobility and daily living.[45]

3. Assessors with specialist understanding

Medical professionals are inappropriate as sole assessors within a social model approach.

The roll out of the personalisation agenda has resulted in a wealth of professionals who would be well placed to carry out an assessment of the type suggested here – for example experts with experience in person-centred planning, transition plans and support plans. Assessors should have a clear understanding of the barriers that drive up extra costs, and be absolutely free of any targets around reducing the number of disabled people on benefits.

4. Indicative decision stage

Disabled people should not be forced to go without support for indefinite time periods if they challenge their assessment decision. They should be given every opportunity to ensure their assessment reflects the barriers they experience which drive the extra costs they face, and given enough time to make the necessary plans in the case of an adverse decision.

Mandatory reconsideration – which disabled people currently have to go through before they can appeal a DLA or PIP decision – should be replaced by an Indicative Stage where claimants can either accept the decision, contend the decision and take the opportunity to submit extra evidence to assessors, or decide that they would prefer to go straight to appeal. In the latter two cases, claimants should have access to hardship payments whilst waiting for a further decision.

5. Signpost to support

PIP assessments should be seen as an opportunity for the Government to support disabled people more holistically.

The assessment should note when a claimant would benefit from additional support besides that provided by PIP – for example whether housing, social care, employment support, or financial advice would help remove barriers and promote independence.

6. Financial eligibility

Extra costs payments should not be means-tested

There are many advantages to not means-testing – it reduces the administration costs associated with a benefit and minimises disincentives to work that may exist elsewhere in the social security system (if a disabled person moves into employment they will not lose their DLA or PIP). It also means that the payment continues to go to those who face the greatest financial penalties, rather than to those with lower incomes.

3. Extra costs payments do not go far enough

Chapter two looked at how DLA and PIP payments are crucial for disabled people's independence and participation. It argued that the planned cap on AME must be designed so as to protect these crucial payments and that assessments for extra costs payments must ensure that those who need financial support to offset these costs receive it.

This chapter will bring together evidence that shows that, despite DLA and PIP, disabled people experience considerable financial instability because of extra costs, and argues that ending this financial penalty is an economic imperative for the Government. Part of doing so will involve placing a 'triple lock' on these payments.

Extra costs payments do not cover all disability-related costs

The data we have available suggests that disabled people spend much more on average on costs related to their disability than they receive on average through extra costs payments. In 2015/16 disabled people will receive around £360 a month in DLA or PIP payments.[46] This is substantially lower than the latest estimate we have of extra costs – £550 a month.[47]

Fewer people are getting support and the support people get is decreasing

A 20 per cent cut to the budget for DLA will mean 600,000 disabled people lose their support through stricter eligibility criteria and regular reassessments. In addition, extra costs payments are now uprated each year by the consumer price index (CPI), rather than in line with the retail price index (RPI).[48] Between 2010 and 2017, 3.25 million DLA claimants will be £1,000 worse off because of this change.[49]

Other areas of support that could mitigate extra costs are also dwindling. From April 2013, the Social Fund, which provided interest free community care grants and crisis loans to help nearly one million disabled people meet immediate financial pressure,[50] was abolished and replaced with localised schemes.

Households with a disabled person are **twice as likely** as households without to have unsecured debt totalling **more than half** their income

However there is no statutory obligation for councils to continue providing this financial support and government funds are not ring-fenced.

At the same time, some of the things disabled people need to buy are very expensive.

For example some disabled people must pay for a £4,000 stair lift, a £5,000 mobility scooter, or an electric wheelchair which can cost between £900 and £6,000.[51]

Disabled people are more likely to be in debt

On top of having lower incomes generally,[52] and despite the provision of DLA and PIP, extra costs leave disabled people with less disposable income. Having less cash to spare makes it harder to afford the basics in life and respond to financial shocks.

The evidence of this is clear – households with a disabled person are twice as likely as households without a disabled person to have unsecured debt totalling more than half their household income (16 per cent compared to 8 per cent of households overall).[53]

A Scope survey found that a large proportion of disabled people are relying upon credit to meet their basic needs – half (49 per cent) of disabled people have used a credit card or loan to pay for everyday items in the previous 12 months,[54] most commonly to pay for clothing and food. Disabled people are three times more likely to turn to doorstep and payday loans. One in 10 (10 per cent) surveyed had a cash loan from someone who came to their home compared to three per cent of non-disabled people.[55]

Some of this can be accounted for by the rising costs of goods overall, the impact of the abolition of the Social Fund,[56] and the lower incomes of disabled people. But it is also indicative of the current inadequacy of extra costs payments to cover the additional costs they face.

Not only is being in debt, or without enough money to cover essentials, bad for disabled people, it can also result in costs to the Treasury – for example more people drawing upon local welfare assistance in times of emergency. The planned 20 per cent cut to the PIP budget does not reflect the impact costs of taking support away from disabled people.

Disabled people are less likely to be able to save for now and for the future

Having higher costs and lower disposable incomes also means that disabled people are considerably less likely to be able to save. Individual savings can act as buffers against debt, but they also enable people to plan for retirement, pay for education, training and re-training, re-location in pursuit of career advancement, and to save and plan for a family and their children's future.[57]

"My essential outgoings are just about covered leaving me with no ability to save for future things. Plus I have had to cut my travel and social activities to less than a tenth. This has made it hard to network and make contacts to help me find work and has left me extremely isolated." Leah, London (Living standards survey, Scope)

Research shows that disabled people already find it harder to protect themselves against financial shocks than non-disabled people. In a recent survey, over a third (37 per cent) of disabled people said they could not afford an unexpected but necessary expense of £500 compared to a quarter (26 per cent) of non-disabled people and 73 per cent said they had not saved in the last year.[58]

On average disabled people are likely to have £108,000 fewer household savings and assets than non-disabled people. This is even after we take into account other factors which could be driving the difference such as the fact that disabled people have, on average, lower educational qualifications, lower socio-economic status and lower 'earning potential'.

"About two years ago I had getting on for £7,000 and now I have under £3,000. Getting my vehicle insured cost £800. DIY to my flat… and getting various alterations to my flat and room here… they are all quite big expenses. Like replacing and maintaining ramps and upgrading my heating system which has meant a £50 increase in my rent." Tom, 42, Nottingham, (Living standards interview, Scope)

"I would like to save but recently have had to buy or pay out for things like a wheelchair, my Motability car, raising chair. I want to earn more but all the higher paid jobs require travel or doing things I can't access." Sara, 27, Wickford (Living standards survey, Scope)

New research shows that disabled people enter retirement with considerably lower private pension wealth than non-disabled people. Without savings, housing assets or private pension wealth – disabled people have half the level of savings of non-disabled people by the time they reach retirement age. In the 55-64 age group, the gap in the mean level of private pension wealth is £125,000 and the gap at the median is £75,000.[59]

"I had to cash in my pension so that I could get a lump sum to purchase a mobility scooter, as my walking has deteriorated. When the benefits agencies were told, I had to send in my bank statements and my benefit was lowered. Again it is like being penalised for being disabled. Without that scooter I would be house bound a lot of the time." Donna, Warrington, 50 (Living standards interview, Scope)

This problem has implications for the future living standards of the whole of society. We live in a rapidly ageing population. By 2035, the Office for National Statistics (ONS) predicts that

disabled people have **half the level of savings** of non-disabled people by the time they reach retirement age older people will account for 23 per cent of the population, compared with 17 per cent in 2010 and 15 per cent in 1985.[60] Over a third of the workforce will be aged 50 or over by 2020.[61] This has considerable consequences for public spending. Continuing to provide state benefits and pensions at today's average would mean additional spending of £10 billion a year for every additional one million people over working age.[62] The need for individuals to be contributing to their own retirement income through building more of their own pension wealth has been reflected in many policies introduced by the Coalition Government, for example auto-enrolment and National Employment Savings Trust (NEST).[63]

Disabled people make up a large and growing proportion of the working age population[64] – a trend that will become more pronounced with the introduction of a higher state pension age. They represent a growing, significantly under-pensioned cohort. The inability of disabled people to save due to the extra costs they face is one of the biggest challenges to future living standards in the UK.

Recommendation

'Triple lock' PIP and DLA.

Currently extra costs payments do not cover all additional disability-related costs, leaving disabled people more likely to be in debt, let alone able to build up savings. This poses major challenges to any government committed to protecting disabled people's standard of living.

The Government has placed a 'triple lock' on the basic state pension – meaning it rises by whatever is the highest of CPI inflation, average earnings or 2.5 per cent each year.

There is political consensus on the idea of a 'triple lock' for state pensions,[65] to give older people the financial security to 'fulfil their dreams'.[66] Building on this consensus all political parties must commit to extending the 'triple-lock' guarantee to extra costs payments in the next parliament so that they rise by the higher of inflation, earnings or 2.5 per cent.

Uprating extra costs payments by average prices is inadequate. Firstly, as we have seen, the prices people face for goods and services relating to their disability are not 'average'; they are often specialist and very expensive. Secondly, extra costs payments are used to purchase both goods and services. In the latter case, disabled people use their DLA or PIP to pay people's wages, for example physiotherapists, or someone to help with essential household tasks around the home. Demos survey data showed disabled people were spending on average nearly £65 a month on household tasks, and over £40 a month on therapy.[67] As earnings begin to rise higher than prices,[68] having DLA and PIP rise only in line with prices will mean disabled people's disposable income is further diminished.

The Government can still reduce their spending on extra costs payments, whilst triple locking them – but it means that spending on these payments will decrease at a slightly lower rate than planned. Placing a 'triple lock' on DLA and PIP from April 2014 onwards would reduce the amount saved by a total of £1.1 billion by 2020 / 21; around £180 million each year, and around £45 million in the first year of the next parliament.[69] In addition 'triple-locking' has potential wider benefits. More closely aligning extra costs payments with expenses disabled people face now and in the future means that they will be better placed to take up opportunities when they arise, for example entering into employment and participating in their community.

4. Tackling the drivers of extra costs

The previous chapters have explored the crucial role extra costs payments play in raising disabled people's living standards, and protecting future living standards in the UK.

It is important that Government take the steps outlined to protect crucial extra costs payments and to ensure all of those who need support in covering these costs get it.

But protecting state-funded extra costs payments and making them go further will not end the financial penalty disabled people face. The Government must gain a better understanding of how extra costs could be driven down, and all relevant departments must be responsible and accountable for doing so.

On top of this, markets are not working well for disabled people, which is driving up extra costs. This is an under-researched area of policy, and in 2014 Scope will be running a Commission into Extra Costs to examine the role local and national government, business, regulatory agencies and disabled people all have in tackling the key drivers of extra costs.

All departments can play a role in driving down extra costs

Currently the only Government department with responsibility or accountability for extra costs is the DWP.[70] But often the sources of extra costs arise in policy areas that are within the remit of other departments. For example, research shows that inaccessible housing can contribute to extra costs – there is a strong correlation between suitability of housing and disability-related spending.[71] Inaccessible transport is also a key driver of extra costs – a survey of over 2,000 disabled people, conducted by the Papworth Trust, showed that more than half of disabled people who receive DLA use it to pay for specialist transport.[72] The inaccessibility of public buildings and public services can drive up costs.[73]

It should be a priority for all Government departments to address poor performance that perpetuates higher costs for disabled people. For example, if the Department of Transport made positive steps towards commissioning operating companies that increased the accessibility of public transport, this would decrease the demand for support from the PIP mobility element.

Recommendation

Ensure truly cross-departmental policy-making to identify and drive down the root causes of extra costs.

All political parties must commit in the next parliament to enacting a fundamental shift towards a cross-governmental and cross-sector approach to rebalancing markets and driving down extra costs.

Truly sustainable solutions that will bring spending down without compromising people's living standards will involve taking a whole-government approach to tackling the drivers of social security spending. This means not just cross-departmental collaboration but also cross-departmental accountability for taking action to reduce unnecessary costs.

One potential way of achieving truly cross-departmental working will involve the Treasury working with the Minister for Disabled People across Government to identify areas of preventative policy that can reduce the overall costs disabled people incur, thus driving down social security spending. It could be done through within-departmental or cross-departmental funding mechanisms such as an AME-DEL switch.[74] It could be achieved by strengthening the role of the Office for Disability Issues (ODI), by placing it in the Cabinet Office, or placing the ODI at the heart of scrutiny that is intended through the AME cap.

Some things disabled people have to buy are unjustifiably expensive

Assistive technology helps many disabled people live more independently and contribute to the economy, but can be prohibitively expensive for disabled people to access. For example, Lightwriters – which turn text into speech – can cost up to £3,500 and pieces of assistive technology that enable a person with a visual impairment to read a paper letter or other document can cost between £500 and £2,000.[75] A communication device made through modification of a mainstream tablet computer or smartphone will be cheaper than a dedicated specialist device, because the development and production cost of the mainstream components is be spread across the hundreds of thousands of mainstream devices produced, rather than across the small number of assistive devices.[76] But the products that could modify mainstream devices do not currently exist in the market. As outlined previously, disabled people are sometimes financially excluded, meaning that they pay more for financial products and services, for example paying a higher premium on travel insurance because of a condition they may no longer have.[77]

The market for disability equipment has been found to be working badly for disabled people, resulting in often unfair prices. A study by the Office for Fair Trading (OFT) showed a huge variation in prices of identical products. The prices for the same brand and model of scooter often vary by over £1,000 and can be as high as £3,000.[78]

In 2014 Scope will be running a Commission into Extra costs to examine ways in which the key drivers of extra costs can be driven down through re-balancing markets, including:

- How businesses can recognise and harness the power of disabled people as a consumer base, for example through following certain 'design principles' in producing products which can modify mainstream devices.[79]
- How industry can be incentivised to innovate for accessibility – for example through creating a new

funding stream as part of the Growth and Innovation Fund (GIF) from the Skills Funding Agency which invites employers in the relevant sectors to apply for investment in skills of their workforce to innovate for disabled people.

- How the Government or others can use their spending power to bulk buy essential equipment, similar to the Motability scheme which buys thousands of cars and mobility scooters at cut price so that they can be leased to disabled people at DLA higher mobility rate.
- How disabled people could harness their collective spending power, for example by pooling DLA and PIP payments.
- When regulatory agencies, such as the Office for Fair Trading, must step in to re-set the balance between consumer and provider market power.
- How consumers can be empowered through information provision and market transparency, for example via online disability-specific consumer forums and communities.
- When the Government and regulatory agencies must step in to end the financial exclusion of disabled people and how we can ensure they are at the heart of emerging markets and policies relating to income protection and affordable pensions.

Conclusion

This report is the second in a series that looks in depth at the challenges that disabled people face in both making a contribution towards economic growth and also benefiting from an economic upturn.

Disabled people have to spend more to live. They encounter extra costs in all areas of life, and must spend often large amounts to meet their needs. These extra costs absorb much of disabled people's income, and mean that there is little disposable cash left over to spend on essential items, or to put aside for later life. This means disabled people are using credit to pay for the basics, and are almost never able to build up their own financial safety net. This has implications for the success of pensions reform and therefore for the living standards of the UK for generations to come. So long as we leave this problem of extra costs unresolved, we will be unable to enter into sustainable, fair economic growth.

In the lead up to the 2015 elections, we propose a multi-pronged policy approach to ending the financial penalty disabled people pay on life. The first stage is to protect the crucial payments the Government provides disabled people to help meet the extra costs, and to make sure those people who need support receive it. The second stage is to make sure extra costs payments are more generous by placing a 'triple lock' on them. The third stage is to look at a much more long term sustainable approach to driving down extra costs. This will involve all parties committing to a fundamental shift to ensure departments can work together to drive down extra costs. It will also involve rebalancing markets so that disabled people get a fairer deal.

The impact of taking these measures will have both short and long term effects on disabled people and wider society. Protecting extra costs payments in the short term and driving down extra costs in the long term will go some way to ensuring that there is fair, inclusive growth which does not leave disabled people behind.

The third report in this series will look at what the Government can do to create better job opportunities for disabled people.

Annex

1. Methodology

- Scope commissioned Demos in 2010 to investigate the extra costs disabled people face and the drivers of these costs. We present new analysis of this data.
- Scope commissioned Ipsos MORI in 2012 to examine all areas of disabled people's financial wellbeing, including financial wellbeing of disabled people across topics of credit and debt, savings and insurance, and information and advice.
- Scope commissioned the Centre for Economic and Social Exclusion (CASE) at the London School of Economics (LSE) in 2013 to produce an in-depth research report examining the disability wealth penalty.
- Scope ran a survey with over 1,000 completed responses from disabled people[80] and conducted over 50 in-depth qualitative interviews providing a wealth of evidence on the financial pressures facing disabled people and families with disabled children.
- Scope asked disabled people to tweet their uses of DLA, and compiled these tweets on a Scope blog.[81]

2. Table behind Demos survey data

Interval (amount spent per month, £)	Percentage
0–49	1.1 per cent
50–99	4.2 per cent
100–149	5.7 per cent
150–199	7.3 per cent
200–249	3.9 per cent
250–299	4.3 per cent
300–399	6.5 per cent
400–499	18.6 per cent
500–599	13.8 per cent
600–699	11.2 per cent
700–799	6.1 per cent
800–899	3.9 per cent
900–999	3.1 per cent
1000–1499	6.5 per cent
1500–1999	2.6 per cent
2000–2499	0.9 per cent
2500+	0.4 per cent

3. Triple lock of PIP and DLA calculation

Costing the triple lock of PIP and DLA was done using the Department for Work and Pensions forecasts of spending on both of the payments in the years up to 2017/18, accessible here https://www.gov.uk/government/publications/benefit-expenditure-and-caseload-tables-2013. Using March 2014 Office for Budget Responsibility forecasts of CPI and average earnings, accessible here http://cdn.budgetresponsibility.org.uk/37839-OBR-Cm-8820-accessible-web-v2.pdf we calculated the cost of up-rating DLA and PIP spending by each measure of inflation, for the years up until 2017/18. Looking at the forecasts for inflation, we were able to see which would be the greater of average earnings, CPI or 2.5% in the years up to 2017/18. We could then calculate each year the difference in cost between uprating by CPI, or by whichever was the highest out of CPI earnings and 2.5. We extrapolated beyond that to 2020/21. The cost each year, for both DLA and PIP, are below.

For DLA

2014-15	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21
£0	£66.4m	£158.3	£201.2	£241.9	£282.8	£323.7

For PIP

2014-15	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21
£0	£13.6	£74.2	£223.6	£393.9	£564.2	£734.4

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Scope

About disability

Scope exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here.

We provide support, information and advice to more than a quarter of a million disabled people and their families every year. We raise awareness of the issues that matter.

And with your support, we'll keep driving change across society until this country is great for everyone.

Disabled and been priced out? Share your experiences and have a conversation on Twitter about extra costs and disabled people's #living standards

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