

Thurrock Coalition



Response to the Department for Work & Pensions Consultation on Aids and Appliances and the Daily Living Component of Personal Independence Payment (PIP)

About Thurrock Coalition

Thurrock Coalition is the User-Led Organisation for Thurrock. We are a company that has been set up to ensure that people who live in Thurrock have access to all the information they may require to get the support and care that they need.

Thurrock Coalition is an 'umbrella' company that consists of 4 organisations, all of which follow the Social Model of Disability and aim to improve the lives of disabled and older people living in Thurrock by seeking to remove environmental, attitudinal and physical barriers that exist in society. We connect to over 1500 individuals and organisations with an interest in disability issues.

1. General Views on the current criteria

Personal Independence Payment, as with DLA, is a vital source of independence for Disabled people. The positive impact of entitlement PIP is multi-faceted in improving full enjoyment of civil, social, economic and cultural rights of Disabled people, particularly given the effect of the Enhanced Rates "passporting" to other schemes. It is important not to make the entitlement criteria so strict so that vast numbers of Disabled People suddenly become ineligible and have to seek support from statutory services and other sectors that are already experiencing funding pressures.

Receiving a regular fixed monthly sum is beneficial as it provides consistency and certainty for Disabled people and ensures that budgeting is made more straightforward for individuals, family members and carers who provide vital support.

2. General Views relating to all of the 5 Proposals

Essentially, all of the proposals, if implemented, will remove or significantly reduce the number of people eligible for either rate of the Daily Living Component of Personal Independence Payment. However, people with significant ongoing and fluctuating conditions are likely to be left without the support they need if the proposals are implemented.

The proposals are reached on the assertion that once an individual has bought this equipment using PIP, then they are no longer disabled and therefore should not get the ongoing monthly payment.

This assertion however, has no regard for ongoing costs of living with an impairment – (the added costs penalty) or the need for ongoing support and the need to purchase, maintain and replace such items of equipment.

Further, the proposals fail to take into account the fact that although Internet access is important in identifying relevant Aids and Appliances, Disabled people are 20% less likely to have access to the Internet than their non-disabled peers. If these proposals are implemented, then more should be done to introduce support and subsidies to enable disabled people to access the Web.

Who will be affected:

The proposals will in effect create a hierarchy of impairments for equipment – people with sensory impairments will be more affected than people with learning difficulties, and could feel penalised for using Aids or Appliances.

Relatives/carers will have to foot the bill, who will also be unable to access entitlement to Carers Allowance if the Disabled person for whom they care loses entitlement to Enhanced Rate of PIP as a result of the new Proposals, and then has to turn to other services, which themselves are facing increased funding reductions.

For example, this will impact upon Local Authorities who will struggle with rising demand, and an ageing population which may result in the Authorities not fulfilling their Statutory Duty to reduce, remove or delay the need for care (under the Care Act 2014).

We are concerned about people who have life limiting conditions, particularly as to whether their potentially revised provision of PIP be sufficient.

Furthermore, many specialist Aids and Appliances are not low cost and often incur an expensive initial outlay, followed by expensive ongoing insurance costs.

In addition, many councils have now stopped providing assistive small items of equipment that cost under £50, in order to realise savings, meaning that avenues for equipment, choice and control will be reduced still further if the latest PIP proposals are implemented.

Simple Aids for daily living

Simple Aids to daily Living are an effective way to help people maintain independence in the home and outdoors.

Whilst there are a variety of items on the market to help with daily living activities, Disabled people face several barriers in accessing such items. For example, Disabled people are half as likely to be employed and half as likely to have no educational qualification¹ as their able bodied colleagues.

According to the Employers Forum on Disability, one in five disabled people in the UK are unemployed but want to work; this compares to one in 15 of non-disabled people. 44.3% of working age disabled people are economically inactive. This figure is nearly 4 times higher than non-disabled people (11.5%). Disabled people are 4 times more likely to be out of work than non-disabled people. (Joseph Rowntree Foundation 2014).

The changes would also disproportionately impact Disabled people in terms of their economic situation, given that disabled people are less likely to be employed and thus economically active compared to non-disabled people:

According to the Labour Force Survey, disabled people are now more likely to be employed than they were in 2002, but disabled people remain significantly less likely to be in employment than non-disabled people. In 2012, 46.3% of working-age disabled people are in employment compared to 76.4% of working-age non-disabled people. There is therefore a 30.1 percentage point gap between disabled and non-disabled people, representing over 2 million people. The gap has reduced by 10 percentage points over the last 14 years

¹ See DWP Office for Disability Issues – Disability Facts & Figures. Available at: <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures>

and has remained stable over the last two years despite the economic climate.²

The vital support provided by disability-related Aids and Appliances and the positive difference such equipment can make to the lives of disabled people makes it an important area to consider further.

The Disability Digital Divide presents an additional and pervasive barrier to disabled people accessing the Internet, and in turn limiting the ability of purchasing cheaper equipment themselves.

The potential for the Internet and mainstream technology to have a positive impact upon Disabled people (of whom there are 11 million nationwide) is yet to be realised. A recent report from Scope and the Helen Hamlyn Centre for Design³ highlights the following issues that need to be addressed:

- Disabled people still face a huge digital divide – and that many still have to choose between expensive specialist equipment, or inaccessible mainstream gadgets.
- Technology built for disabled people is expensive, has low functionality, and often requires specialist knowledge to adapt.
- Mainstream technology, like iPads and Windows Tablets, is cheaper and can do much more, but is rarely customised to meet disabled people’s needs.

It is suggested that emphasis needs to be placed upon improving the information available to disabled people about enabling technology. Disabled people are amongst the groups least likely to use the internet, and are 20% less likely to be online than their peers. This is despite the huge potential of services like online shopping and banking to transform the lives of disabled people.⁴

² DWP Office for Disability Issues – Disability Facts & Figures. Available at: <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures#employment>

³ See: Helen Hamlyn Centre for Design – “Enabling Technology” Available at: <http://www.hhc.rca.ac.uk/CMS/files/1.Enabling%20technology%20report%202013%20digital%20technology%20disabled%20people%20Scope%20Helen%20Hamlyn.pdf>

⁴ Scope “Enabling Technology” – Jewell, S and Atkin, R. September 2013. Available at: <http://www.hhc.rca.ac.uk/CMS/files/1.Enabling%20technology%20report%202013%20digital%20technology%20disabled%20people%20Scope%20Helen%20Hamlyn.pdf>

Therefore, the DWP should look at ways of supporting Disabled people to access the Internet and accessible technology as a preventative way of reducing and delaying the need for care alongside the provision of PIP.

The DWP should review at least some of the proposed changes to assessing the Daily Living eligibility of PIP in light of the budget announcement on the increase in minimum wage. The cost of paying for carers on minimum wage is going to increase by at least 10% from next April (2016) and then 6% a year for the following 4 years. There is going to be a significant increase in the cost of care which is going to have to be met.

Flexibility for the Disabled person as to how PIP is spent is beneficial, especially as one size does not fit all, and needs vary.

In line with Government policy, people should be supported to exercise real choice and control over their lives in accordance with the International Convention on the Rights of Persons with Disabilities 2006⁵ and the Right to Independent Living enshrined in Article 19.

Independent Living is a particularly important area that requires urgent government attention given that “Over a quarter of disabled people say that they do not frequently have choice and control over their daily lives.”⁶

It must be noted that such specialised equipment, even if small, is essential to support disabled people to live independent lives. The price tag often associated with purchases (especially if bought on the High Street from specialist retailers) of this kind can take up a high proportion of the income of disabled people, their families and carers, and either a one off sum or lower monthly payment is unlikely to meet this need.

Views on Option 1 – Provision of a lump sum

We are concerned about the lack of information and detail relating to the inevitable administration costs of any voucher scheme, including the procurement and tender processes and award of contract to suitable providers

⁵ See the full text at: <http://www.un.org/disabilities/convention/conventionfull.shtml> Signed by the U.K. Government on 30th March 2007, and Ratified by the U.K. Government on 8th June 2009. See: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en

⁶ Source: ONS Opinions Survey 2011

with the training and understanding to deliver a good quality and timely service to Disabled people.

More details are needed as to how long any such award or entitlement would last, how any review system would operate or how ongoing maintenance, repairs or insurance would be addressed. When determining length of awards the decision makers need to take into account the anticipated life cycle of a piece of equipment and be flexible to reflect individual needs and conditions that may result in greater use, wear and tear and thus a reduction in the duration of use of any particular item.

Clarity is also required on how current recipients will be reviewed. Will this be in line with current award lengths, before any change to award can be made?

Furthermore, we would like further details as to how often people will be able to apply for a daily living lump sum award if this proposal is implemented. If someone applies for PIP and goes through the assessment process, then 3 months later their needs change as their condition worsens, they then require a piece of equipment in addition to the original item, will they need to go through another application process, meanwhile their needs are increasing, leading to further additional support needs? How does this reconcile with the national “Prevent, Reduce, Delay” agenda?

In addition, Disabled people already face an added costs penalty of living with an impairment, as evidenced by a recent Scope report following the Extra Costs Commission Independent inquiry into extra costs for disabled people.⁷

Having less support means peoples’ conditions become more likely to deteriorate and require more costly support in the longer terms, also carers may have to increase the remit of their unpaid caring role and care for longer, and could then themselves become ill.

In addition, the consequences of implementing the proposals are manifold – affecting disabled people, older people and family carers. Individuals would lose not only PIP, but entitlement to Carer’s Allowance and other “passport” benefits, and the changes would significantly increase the number of disabled people affected by the benefit cap.

⁷ <http://www.scope.org.uk/get-involved/campaigns/extra-costs-commission>

People will become more isolated which could lead to mental health conditions, and a potential increase in suicides.

Altering the eligibility threshold serves to cause anxiety, and uncertainty for individuals and advice organisations alike, which will in turn result in undue stress for already vulnerable Disabled people.

In terms of safeguarding, providing a one-off lump sum, perhaps through a voucher scheme, raises concerns about the additional costs to the Disabled person relating to installation, review, appropriateness and correct usage of Aids and Appliances. Feedback indicates some concerns if the DWP tightens the eligibility for the Daily Living component of PIP.

Our members would like clarification as to how any equipment purchased will be safely, properly and correctly set up, installed and fitted to ensure safe usage by the Disabled person. If Disabled people are unable to afford these additional costs, the saving of money on the equipment provision and the installation thereof, risks the health and well-being of vulnerable people who may, slip, trip or fall as a result of incorrectly installed equipment breaking or coming away from the wall(s).

The preventative nature of Aids and Appliances becomes redundant if an incorrect installation or set up or induction (by untrained friends, family or community members) results in an even short term hospital admission and subsequent healthcare intervention and/or treatment.

It is likely that more people will appeal such decisions to provide a lump sum rather than a weekly payment, leading to stress in a system which is already under pressure.

Views on Option 2 – Provision of a lower monthly payment

This proposal essentially introduces a “lower-rate” Daily Living Component for PIP, similar to the Low Rate Care Component for Disability Living Allowance previously. This option appears to be the most sensible, if a change has to be made. It recognises that those with lower level support needs still require some ongoing assistance to live as independently as possible and to avoid the need for costly health interventions.

In relation to Option 2, if an individual’s needs change and their conditions worsen, they should be encouraged to apply again, as now, but the DWP need to factor in the administrative cost implication of this scenario, against the

costs of the current system. Perhaps by introducing a “fast track” review system for any changes to needs or repair or replacement for Aids and Appliances during and throughout any current award of the proposed lower monthly payment.

This option would meet the original Policy aim whilst preserving the consistency and certainty of receiving a regular, fixed monthly sum and would therefore help people who struggle to budget with larger sums.

Option 2 also retains flexibility for people, as they would still be able to save up the proposed lower Daily Living Component to purchase more suitable, better quality, more robust items of equipment rather than the opting for cheaper, less appropriate items. Also, if the cheaper items are more prone to breakages, then the exercise becomes a false economy if repeated replacements and repairs are required.

Views on Option 3 – Introduction of a New Rule that people must score some points for daily living that are not due to the use of Aids or Appliances

This proposal, if implemented, must recognise the multi-faceted nature of people’s impairments, it is highly likely that individuals will score at least some points across the various descriptors. This option is not preventative. It is too limited and overly restrictive as it would only be suitable for people with higher ongoing costs.

The assessment process should become more flexible if this proposal is implemented in order to fully explore the nature of peoples’ conditions, particularly if these fluctuate, and how impairments affect Daily Living, especially on “bad days” so that the correct number of points are awarded in each case. This would also lead to a reduction in numbers of Reconsiderations and Appeals.

Views on Option 4 – Changing the meaning of “Aids and Appliances”

Tightening eligibility criteria for equipment by changing the meaning of Aids and Appliances will have a negative and adverse effect upon the ability of Disabled people to live independently. The reference to “low cost” items or free items is arbitrary and fails to take into account the fact that what is “low cost” to one individual may not be so for another, even if the needs and assessment results of two individuals are similar.

PIP is supposed to provide support to meet the added costs of living with an impairment, and as noted above, Disabled people already face economic barriers in society. In addition, pressures upon both Health and Social Care budgets mean that fewer and fewer items, including Aids and Appliances are being provided as part of the Local Authority “catalogue” of small items of equipment⁸ and so Disabled people are having to look to purchase these themselves.

But if access to necessary and vital equipment is curtailed through the proposed changes to PIP, Disabled people will suffer, their conditions could worsen, leading to re-application for PIP, an evident level of increased needs since initial assessment, thus scoring of more points than previously and therefore costing Central Government more in the long term.

Again, if the cheaper items are more prone to breakages, then the exercise becomes a false economy if repeated replacements and repairs are required.

We would like clarification on how the system for determining exactly which items are “a poor indicator of additional cost and need”.

Views on Option 5 – Changing the number of points scored for using Aids or Appliances from 2 to 1.

PIP currently takes into account individuals’ need to use Aids and Appliances to complete the assessed activities, awarding two points – the lowest level – scored for most questions, such as “needs to use an Aid or Appliance to be able to dress or undress” and “needs to use an Aid or Appliance to be able to speak or hear”.

The proposal fails to recognise the importance and gravity of Daily Living Activities and the need to use Aids and Appliances, especially in terms of enabling people to live independently (as enshrined in Article 19⁹ of the United

⁸ See The Care and Support (Charging and Assessment of Resources) Regulations 2014, Reg. 3.

⁹ Article 19:

- Disabled people have an equal right to live in and take part in the community.
- Disabled people have the right to the same choice and control as non-disabled people.
- Governments should do everything they can to ensure disabled people enjoy these rights.
- Governments should ensure that:
 - disabled people have the right to choose where they live and who they live with – no disabled person should be unlawfully forced into a particular living arrangement (for example be forced to live in a care home against their will)

Nations International Convention on the Rights of Persons with Disabilities 2006¹⁰) and also fails to have regard for preventing, delaying and reducing the need for more costly health and care interventions that would be needed in the absence of the support currently provided by the Daily Living Component of PIP.

If this option is implemented the Assessment should be modified in such a way so as to identify an actual need rather than a preferred need. Disabled people often do not have a choice as to whether to use an aid or appliance, it is a matter of having to in order to function on a daily basis and to be able to live with dignity.

Reducing the number of points awarded fails to appreciate the scale of difficulty faced by Disabled people and the degree to which Aids and Appliances alleviate such barriers, particularly around the home. Reducing the number of points awarded in this regard will mean that Disabled people become much less able to live with dignity, choice, control and independence in their local communities.

Conclusion

It is recommended that the DWP give due consideration to the points and concerns raised in this submission as it is evident that all of the Proposals contained within the Consultation will have far reaching consequences for Disabled people, their families and carers.

We are of the view that **Option 2**, (lower monthly payment) - whilst not preferable to the current system of eligibility, it is the most equitable option. **Option 2** recognises the importance of ongoing support through PIP for people who score all their points for Daily Living via the use of Aids and Appliances, by enabling people to maintain personal dignity, physical and mental health and emotional wellbeing, personal safety, control by the individual over day to day life, participation in work, education, training or recreation, social and

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- disabled people have access to a wide range of support services (at home and in the community) including personal assistance to prevent isolation and support inclusion
 - disabled people can access the same community services as everyone else.

¹⁰ See the full text at: <http://www.un.org/disabilities/convention/conventionfull.shtml> Signed by the U.K. Government on 30th March 2007, and Ratified by the U.K. Government on 8th June 2009. See: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en

economic wellbeing, domestic, family and personal life and an individual contribution to society.

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