**Response on consultation on aids and appliances and the daily living component of Personal Independence Payment (PIP)**

**5th January 2016**

Introduction

LCiL is a user-led charity, working with disabled people to enable them take control of their lives and live independently in the community. All our services respond to needs identified by disabled people and offer a range of practical and emotional support to promote their equal participation in all aspects of society.

This submission has been drawn up using some of the experiences and views of disabled people in Edinburgh and the Lothians, including users of LCiL services.

For more information about LCiL visit our website: [www.lothiancil.org.uk](http://www.lothiancil.org.uk)

General:

* 1. Of late our disability rights and information service has been inundated with requests from disabled people and people with long term conditions in Edinburgh and the surrounding area, who require assistance with Personal Independence Payment (PIP), (including new claims; those whose award is subject to an ‘intervention’ up to 12 months prior to it expiring); and since October 2015, those on Disability Living Allowance (DLA) indefinite awards being reassessed for PIP.
	2. We are concerned that this consultation includes proposals which could significantly change the assessment criteria for PIP. It also comes at a time when Scotland is taking views on its new social security system which we have fed into via the Scottish Government’s processes and are supporting disabled people to have an ongoing dialogue about what kind of a system disabled people and carers would like to see.

1.3. Up until now there has been uncertainty and mistrust around PIP, due to the focus on public expenditure cuts which accompanied the roll out of it. This consultation seems to only further emphasise this with suggested measure outlined in the consultation document. We outline our response below.

**Responses to question 1 in consultation document:**

2.1. At present the current payment system of PIP doesn’t restrict how and when a claimant has to use their benefit. PIP, like DLA, was established to offset the additional costs associated with living with an impairment or long term condition. Leonard Cheshire Disability research shows that disabled people have about 25% extra costs compared to non-disabled people, these costs may relate to but will not be restricted to:

* additional heating requirements;
* purchase, maintenance and repair of disability related equipment;
* specialist dietary requirement;
* specialist clothing;
* daily living aids;
* replacement clothing due to frequently wear and tear;
* therapies e.g. physiotherapy, massage, pain management or to benefit their mental health;
* higher transport costs due to inaccessible public transport;
* help with cleaning and other domestic tasks.

A Scope study found last year that disabled people pay on average £550 per month on extra costs related to their disability. PIP as with DLA helps to mitigate the impact of these costs.

2.2. The requirement for claimants to save their benefit to purchase an aid and/or appliance implies that a claimant would have to set aside a specific amount over a period of time to purchase what may be an essential piece of equipment for them to conduct daily living activities. In the meantime, they may be adapting using other unsuitable means, putting their own safety and health at risk, or requiring additional help and assistance from other people.

2.3. Restricting the amount of benefit a person would receive if they were allocated their points for PIP daily living, solely through the aids and appliances descriptors, would create a two-tiered system and add another layer of complexity to an already complicated and drawn out claimant journey.

**Response to Question 2:**

3.1. In additional to this, a voucher scheme, would only serve to undermine the Guiding Principles under UN Convention for Rights of Disabled People: specifically: “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of person”.

3.2. A prescribed list of aids of appliances would also serve to reinforce the medical model of disability by taking away the autonomy of the claimant to exercise choice over what means may best serve him or her in daily life, and reinforce the perception that disabled people are passive recipients rather than active agents in their own lives.

3.3. Such as system would create a paternalistic view of claimants and would result in a person’s impairment becoming prescriptive as far as the aids and appliances they may choose to use or not. It also ignores those with fluctuating conditions who may sometimes require an aid or appliance or may sometimes require help from another person to complete an activity.

**Response to Question 3:**

4.1. Removing ‘pass-porting arrangements’ would not only adversely affect claimants, but also their carers and family members. For example, at present either rate of daily living acts as a passport onto carer’s allowance as well as other additions on means-tested benefits. To remove such entitlement would trigger many low income families into a further spiral of debt and reliance on hand-outs (i.e. foodbanks) and further put pressure on local services and charitable grants/trusts.

4.2. In Scotland either rate of PIP daily living component also acts as a passport onto the national concessionary travel scheme which many disabled people benefit from to maintain links in their civic, social and economic life. To remove this and other passports, would only serve to further isolate and restrict the opportunities of disabled people in their communities.

**Response to Question 4:**

5.1. At present the ‘aids and appliances’ assessment for PIP daily living, implies that a person uses their chosen device in order to complete an activity. It does not take into account the underlying need for this device and/or the manner in which a person does the activity, either with or without an aid or appliance. We have found there is often a lack of consideration given to the information which is on an individuals’ claim form and often the *reliability criteria* are ignored. For example, the assessment must take into account the person’s ability to do a task: safely, and/or repeatedly, and/or within a reasonable time period, and/or to an acceptable standard. (link available here: http://www.legislation.gov.uk/uksi/2013/455/regulation/2/made). This point is emphasised using specific examples below.

**Response to Question 5:**

6.1. Using a prescriptive list of aids and appliances and introducing factors such as whether they are ‘commonly used by non-disabled people for the same purpose as an indication of need’ is an arbitrary basis for determining a person’s entitlement. For example, if a person cannot stand to prepare a meal in the usual way, whether a they use a perching stool, improvises with a bar stool, or prepares the meal sitting at a table, either in an ordinary chair or in a wheelchair is irrelevant. The decision should be made based on the situation of a person with impaired physical or mental function which prevents them from undertaking certain activities without taking special measures to compensate for the impaired function. This also completely ignores the original PIP Regulations 2013 which clearly states an “aid or appliance”- means any device which improves, provides or replaces C’s impaired physical or mental function; and includes a prosthesis”

6.2. The assessment should be based on a person’s need for the aid or appliance rather than aid or appliance they choose to compensate for loss of a particular function.

To exemplify this point further, the alarm system on a mobile phone could be set to go off at regular intervals during the day to remind the claimant to take medication so long as that improves, provides or replaces their impaired mental function, then this should be taken into account as an aid or appliance.

6.3. To introduce another layer of the PIP assessment to determine exactly what may count as a device to compensate a person for loss of function for a particular purpose, requires a degree of precision and technical expertise. This could result in tribunals investigating further what type of supports were used because the claimant could not stand, whether the claimant really needed them or whether they could cope with some other object such as an ordinary stool. This would result in more detailed and resource intensive assessment process to determine entitlement for PIP.

**Response to Question 6:**

7.1. Overall the proposed changes laid out in the consultation document fail to reflect the full picture of people’s disability, and in particular the support, and additional costs, that disabled people need to live an ordinary life, and have the same the same freedom, choice, dignity and control as other citizens at home, at work and in the community.

7.2. We are already seeing people who have claimed PIP, whose condition will not change, or can only deteriorate, who are having to go through the whole process all over again. Proposed changes in the consultation would prompt another review of those who are receiving daily living competent for PIP solely based on points allocated because of aids and appliances. This seems an unnecessary waste of resources, and something that will cause needless stress to disabled people.

7.3 Disabled people currently face many barriers in accessing opportunities in their community, at work and in political life. The provision of vouchers and discretionary payments for those who only score points through aids and appliances in the daily living component of PIP restricts the provision of resources on an equal and inclusive basis. It is our view that individual disabled people should be given choice and control over who provides and what aids and appliances they use in their home, irrespective of their condition/impairment.

7.4. Disabled people have defined Independent Living as: “Disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”.

7.5 The UK Government signed the UNCRDP in 2007. This meant that they agreed with what it said. They then ‘ratified’ the Convention in 2009 which means they promised to do what the Convention says and act to protect disabled people’s rights. If the Government fails to ensure that public authorities are implementing the Convention, then both the Government and those public authorities may be in breach of the Convention. This includes the: Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of person.

**For any questions or feedback on this document please contact:**

Kirstie Henderson
Information and Communications Coordinator.

Lothian Centre for Inclusive Living (LCiL)

Norton Park Centre, 57 Albion Road, Edinburgh, EH7 5QY

Tel: 0131 475 2466

Fax: 0131 475 2392

Email: Kirstie.henderson@lothiancil.org.uk

Website: [www.lothiancil.org.uk](http://www.lothiancil.org.uk)

**References:**

* **Disability and the Downturn:** <https://www.leonardcheshire.org/sites/default/files/Disability%20and%20the%20downturn.pdf>
* **Priced out: ending the financial penalty of disability by 2020, April 2014:** <http://www.scope.org.uk/Scope/media/Images/Publication%20Directory/Priced-out.pdf>
* **The Social Security (Personal Independence Payment) (Amendment) Regulations 2013:** <http://www.legislation.gov.uk/uksi/2013/455/regulation/2/made>
* **Creating A Fairer Scotland: Social Security The Story So Far...And The Next Steps October 2015:** <http://www.gov.scot/Resource/0048/00487055.pdf>