**Briefing paper for City of Edinburgh Council’s Charging Policy Review**

**September 2014**

1. **Lothian Centre for Inclusive Living:** 
   1. This briefing paper has been prepared by the Lothian Centre for Inclusive Living (LCiL). 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.
   2. This includes an information and advice service Grapevine which provides free, confidential information and advice to disabled people, their families and any other organisation or individual looking for disability related information in Edinburgh, East Lothian and Midlothian.
   3. Our Independent Living Support provides support and one-to-one advice that enables disabled people to manage self-directed support packages.
   4. This paper has been drawn up using background information from a number of policy documents relevant to charging policy review and the experience and views of disabled people, including users of LCiL services in case studies in the Appendix on page 6 of this document.

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

1. **Introduction:** 
   1. Understanding the associated additional daily living costs of living with an illness or a disability is essential if local authorities are to avoid charging disabled people more than they can afford for social care services.
   2. Failure to take Disability Related Expenditure (DRE) into account as part of the financial assessment could result in charging levels which cause financial hardship, emotional stress, and restrict the life opportunities of disabled people and their right to live independently in their community.

**Links with poverty:**

* 1. In 2012/13, 20 per cent of individuals in households containing a disabled adult were in relative poverty. For households with no disabled adults, the figure was 14 per cent.
  2. The think-tank Demos has explored the link between the costs of disability and the risk of poverty in the UK. It noted that ‘researchers have estimated that once disability-related costs are taken into account, the numbers of households with a disabled occupant assessed as living in poverty jumps to between 40 per cent and 60 per cent.

1. **Disability Related Expenditure:**
   1. Disability Related Expenditure is not ‘exceptional’ in that these expenses enable a disabled person to maintain an independent life and pay for the additional costs of living with an impairment or long term condition.
   2. 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;
* transport;
* help with cleaning and other domestic tasks.

See appendix for 2 real life case studies from disabled people lay out their additional costs to maintain an independent life.

* 1. Many disabled people face higher day-to-day living expenses, including needing to meet particular dietary requirements, more frequent washing of clothing, more fuel needed to maintain a constant temperature at home, and higher transport costs due to inaccessible public transport. Costs can also be higher because of the need to purchase and maintain essential equipment.
  2. Parents of disabled children face many additional costs, such as the costs of adapting their homes and paying for specialist medical equipment or care services.

1. **Impact of welfare reform on finances of disabled people:** 
   1. Disabled people face disproportionate loss of income due to the welfare reforms introduced since 2010. Research produced by the Centre for Research in Social Policy (on behalf of the Joseph Rowntree Foundation) found that, for disabled people whose sole income comes from benefits, the average deficit between the payments they receive and the minimum sum required to cover all their costs is around £200 per week. This rises to £230 per week on average for disabled people with high to medium needs

Personal Independence Payment:

* 1. A key reform which will affect working-age disabled individuals is the replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP). Some of the key estimations which the Scottish Government have stated in terms of how this will affect disabled people in Scotland include:
     1. 105,000 of the 190,000 working-age disabled people who currently claim DLA will lose some or all their disability benefits by 2018, with a loss of at least £1,120 per year as a result of PIP reassessments.
     2. Approximately 47,000 fewer disabled people in Scotland are expected to receive the PIP enhanced rate mobility component than would have received the equivalent DLA mobility component. Eligibility criteria for the for PIP mobility component is more restrictive than DLA, claimants will only be eligible for the enhanced rate if they are unable to move further than 20 metres, either aided or unaided. This is a significantly stricter criterion than for disabled people who are claiming DLA, who are eligible for the higher rate mobility component provided they are unable to move further than 50 metres (aided or unaided). Even though the mobility component is completely disregarded currently in care charging if someone loses their entitlement it could mean that people are no longer able to purchase small amounts of support to prevent needs from increasing.
     3. Taking any daily living PIP rate into account of assessment for care charges could provide to be an unfair justification of support needs. For example the Child Poverty Action Group has laid their concerns in relation to its assessment criteria. The qualifying activities for PIP do not distinguish between help required during the day or at night. This is in contrast to the assessment criteria for DLA, which recognise that ‘it is much harder to get help at night, particularly for people who live alone’. Under PIP, a disabled person with care needs at night may not score highly enough on the qualifying activities to receive the daily living component. In this case they would face a loss of income of around £54 per week if they have caring needs at night and of around £81 per week if they have caring needs both during the day and at night.

Universal Credit:

* 1. The flagship policy of Universal Credit (UC) has not been fully rolled out as yet, but is due to be introduced in Edinburgh in 2016. DWP expects that 27 per cent of disabled people in Scotland who move onto UC will see an average decrease in entitlement of £37 per week. Other challenges which UC brings in terms of disabled people managing finances include:
     1. Disabled people on Employment Support Allowance who are not in the support group and are at risk of financial pressure due to the benefit cap. The average loss across all households to date is £40 per week.
     2. People with mental health problems or learning disabilities may be particularly likely to struggle with changes to UC payment arrangements. These include the move to monthly payments; and the Housing Element of UC being paid direct to tenants rather than their landlords, therefore they will not see any of this money and it should not be taken into account for care charges.

**The above findings should be considered alongside evidence that disabled people already face higher costs of living and are more likely to live in poverty than non-disabled people.**

1. **Recommendations:** 
   1. It is recommended that local authorities are proactive in gathering information about additional disability related expenses as part of their financial assessment process. Ideally, questions about disability related expenditure should be included in the financial assessment form. This will enable a local authority to decide whether to disregard more of a person’s income or capital, over and above any existing disregards, to take account of any disability related expenditure.
   2. Where a supported person has difficulty in meeting the approved cost of the service due to their financial circumstances, it is recommended that Councils use their powers to abate or waive charges on a case by case basis.
   3. Information on financial assessment processes must be made widely available in plain English in a range of accessible formats including for waiving and abating charges (see section on information). This should include details of the processes by which the authority considers such requests.
   4. Partners and family members are often providing significant levels of care to the person and, as such should be recognised and valued as net providers of care, whose contribution provides a significant saving to both health and social care. They should not face additional hardship simply because they care for their spouse or partner, therefore the partners’ sole income should not be taken into account within a financial assessment. Where a couple have joint income or capital, only the person’s share of this income (no more than 50%) should be taken into account. This is a reasonable approach which takes account of the person’s share of household costs. However, this must be applied consistently and have flexibility to set at a lower percentage share. Furthermore, it should be part of a wider standard financial assessment that takes account of issues such as disability related expenditure (see above).
   5. Scotland Against the Care Tax Campaign (SACT) have also recommended that all local authorities should take account of the Social Model of Disability, the UN Convention on the Rights of Persons with Disabilities and any other related principles on the independent of, and social inclusion of, older and disabled people. Charging policies should be seen within this context and should equally seek to promote the independence and social inclusion of service users. Charging policies therefore:
2. need to be fair and reasonable,
3. take account of the costs of providing or arranging services,
4. take account of the financial means of service users and
5. take account of the financial and other impacts on service users of having to pay charges.

**Appendix – examples of disability related expenditure:**

Case study 1:

Case study 1 is a disabled female who has muscular dystrophy and uses an electronic wheelchair. She requires 24/7 support and requires medical assistance including use of a night ventilator. She does not have a mobility car, but uses the money as part owner of a car, for taxi and train fares as well as the upkeep and running of the car. She also pays privately for a podiatrist to come to the house. She is charged from her income towards the costs of her care but is prohibited from using this to pay for the overheads to cover the costs of employing support staff.

This includes wear and tear, providing suitable bedding for her support staff, heating an additional room for overnight PA support, upkeep of new furnishings for PAs to use such as bed, drawers, tables, etc., all of which are met from her own pocket. This includes breakages by PAs which aren’t claimable on home insurance (i.e. less the excess). These costs occur incidentally but add up.

Estimated staff related expenditure per week includes:

* Laundry, heating, food prep, toilet rolls and electricity – estimate £8 per week
* Travel expenses (train fares, etc.) - £12 per week
* Entrance and refreshment fees - £8 per week.
* As well as the less frequent purchases of furniture, bedding, television.

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She uses her DLA money to pay for basics such as additional toilet rolls, laundry, support staff bedding, heating, escort costs, train fares to visit friends and family, taxis are required to get from door to door, food whilst out, entrance fees for her staff for cinemas/theatre.

Her electricity costs amount up, needing high heating for her own needs as well as daily electric charging for her wheelchair and hoist. Costs also include a ventilator, cough machine, electric door opener and window openers, remote for switches and lights as well as the usual electrical items each household has.

Case study 2

Case study 2 is a disabled male with cerebral palsy. He receives 24 hours a week personal care and a Direct Payment for 2 hours in lieu of day services.

He currently uses the high rate of his DLA care component to cover the following disability related expenditure. This is laid out below:

* Petrol to and from work- £20
* Air cast splint (not available on the NHS) - £1.50
* Shoes- £7.50 (new shoes are required every 2 months due to wear and tear of right sole)
* Podiatrist (Not available on the NHS) - £10 (required every 2-3 weeks at £30 per visit).
* Taxi (when require the use of my electric wheelchair as mobility car is unsuitable) - £22
* Physiotherapy (not available on the NHS) - £15

He is also about to move into his own accommodation which is likely to incur additional expenses in way of removals, installation of adaptations and aids to assist him in daily living which he will be making a financial contribution towards from his disability benefits.

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

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