

## Thurrock Coalition



## Response to the consultation on the closure of the Independent Living Fund (ILF).

### 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. Thus, we have a legitimate and direct interest in the outcome of the consultation on the closure of the Independent Living Fund (ILF).

### The Independent Living Fund in Thurrock

We recognise that on 31<sup>st</sup> March 1993 the Government decided to change the eligibility for the ILF to exclude people over 65 and to apply a different set of rules to new applicants. Many of the original recipients of the fund have now died though 4 still remain in Thurrock. There are an additional 17 disabled people who have been allocated funds since April 1993. We are also aware that in order to receive ILF a person has to be in receipt of the high care component of DLA. There were 790 such people in Thurrock altogether in June 2012<sup>1</sup>.

The 21 ILF recipients in Thurrock, all of whom must receive a basic amount in local authority services (currently £340 a week) to qualify, receive a maximum weekly payment of £475 (in respect of a Group 2 user), and £815 (in respect of a Group 1 user) to supplement the Thurrock ASC contribution of around £370,000. No new applicants have been accepted on the scheme since June 2010. It is contentious whether the ILF was a fund set up to support local authorities temporarily. We understand that the proposals suggest that costs of providing Care and Support must now be met directly from Local Authority budgets.

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<sup>1</sup> ILF User Profile Analysis (Thurrock) – June 2012 (Independent Living Fund) Available at: [www.dwp.gov.uk/docs/user-profiles-0612.pdf](http://www.dwp.gov.uk/docs/user-profiles-0612.pdf)

There are two major implications of the reform. Firstly anyone currently on high rate DLA who loses that rate will also lose ILF – and these are large packages which will have to be picked up, at least in the short term. So 20% reduction in DLA/PIP expenditure will mean a minimum £20,000 a year extra pressure on budgets.

More significantly, though it has not been used well in the past, the fact that ILF will no longer be available implies that the full cost not just the first £340 of every package will have to be met by ASC. As there are already 790 people in Thurrock on high rate care component that would imply a possibility of a huge extra demand on the budgets to pay for those big packages in their entirety in future.

### **General Observations of the consultation and proposals contained therein**

It is not clear whether the existing levels of funding, currently provided by the ILF will be ring fenced and matched like-for-like once the responsibility transfers to Local Authorities.

There are also issues that need to be addressed around the capability and capacity of Local Authorities to administer the ILF funding stream, under considerable budgetary and efficiency saving constraints of their own.

In addition, where the consultation document states that before the ILF passes personal and assessment based details over to Local Authorities, the details of individuals care and support needs will be looked at. Clarification is needed here as to whether this constitute a new assessment of needs or a review of existing needs.

Work needs to be done to ensure that the entire process is inclusive, needs-led and person-centred, with the full participation of the individuals concerned. Due to the vulnerability of people with impairments, we strongly suggest that the government put procedures in place to ensure that the transition over to Local Authorities of provision for ILF funds be carried out in such a way to minimise stress and to prevent risks to independence occurring that would leading to identified needs not being met.

In addition, whilst the consultation document talks about minimising “disruption” to care and support needs, it is vital that Local Authorities undertake support planning with individuals currently in receipt of ILF well in advance of 2015 in order to manage the local impact and consequences of the closure of the Fund.

The purpose, philosophy and scope of the ILF is to be applauded, maximising choice and control for disabled people over their daily lives<sup>2</sup> arguably to a greater degree than the funding provided by Adult Social Care. There are concerns that this inherent flexibility along with the individuals’ choice and control will be drastically decreased once Local Authorities administer the ILF monies. This is particularly problematic

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<sup>2</sup> ILF Policy Circular 6/7/2011: The ILF wishes to promote real choice and control for all our users; we do not expect users to spend the exact amount of the weekly award on care each week. Rather it is for each user to decide how their needs can best be met using the ILF award and to decide how much to spend in any given week. ILF awards can only be used to pay for Qualifying Support and Services (QSS), including any future liability for the cost of QSS. Available at: <http://www.dwp.gov.uk/docs/payments.pdf>

given that the ILF funds care and support needs similar to those categorised as “moderate” under the FACS criteria. (Currently there is only one council in England (Bradford) still funding “Moderate” needs). It can be said that the ILF has applied national eligibility criteria in a consistent way. Adult Social Care has been far from consistent with some councils attempting (and failing) to limit eligibility to “Critical only” under the FACS criteria, and other council introducing “greater substantial” criteria.

The ILF is often used to fund daily living tasks such as laundry, housework, promoting access to the community and social inclusion (commensurate with “Moderate” needs under the FACS criteria).

However, if people who were in receipt of ILF then have to be wholly subjected to Adult Social Care Eligibility Criteria, many of their needs, vital for the maintenance of health and well-being will cease to be met, leading to increased social isolation, inactivity, lack of participation and inclusion in their communities and may well have negative impact upon individual mental and physical health. It is likely therefore that Local Authorities will struggle to cope with the influx of users with a gap in their care and support needs if the Fund is closed.

The consequences of the closure of the Fund has been widely reported in the media:

*“Richard Hawkes, chief executive of disability charity Scope, said the decision to phase out the fund was “bemusing.”*

*“The fund is comparatively very small and is designed to support disabled people to live at home rather than in care homes,” he said. “It’s hard to see how phasing out this fund will do anything but narrow down options and push people towards greater dependence on the state.”*

The phased closure was described as “foolhardy and lacking in humanity” by Labour peer Lord Morris of Manchester.

Lord Morris, who was the first minister for the disabled, said: “This will not save money. If you make it harder for disabled people to live at home, it will cost more because more of them will have to be in hospitals and other places of full-time care.”<sup>3</sup>

## **Adult Social Care Budgets, data collection and the ILF**

It is not clear whether Local Authorities are systematically collecting data on the effects of the cuts resulting in disabled people being left with significantly reduced quality of life as a result of experiencing significant reductions in their adult care budgets or whether accurate projections have been made on the impact of closing the Independent Living Fund from June 2010 (for new applicants) and 2015 (for all current users). This is particularly concerning given that it is likely to mean that no specific data or information exists upon which government can base decisions about the future of the ILF and Adult Social Care Budgets across the country.

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<sup>3</sup> <http://www.bbc.co.uk/news/uk-11985568>

We suggest that more work and data collection is needed before a definitive decision is made. This work would need to assess the cumulative impact of the closure of the ILF upon people, their careers and families in situations where they are receiving a myriad of services provided by Local Authorities. In particular where these services are either being reduced or cut completely or charges for provision of the services e.g. day services, play schemes etc are being dramatically increased, resulting in people being “costed out” of services that they rely upon as part of their quality of life and daily living.

The sheer scale of the Adult Social Care spending cuts should not be underestimated, the impact of which will likely lead to a reduction in independence, quality of life and dignity for disabled people and older people alike:

A recent ADASS budget survey 2012<sup>4</sup> claims that over 85 per cent of the reduction in 2012-2013 will be due to “service re-design and efficiency”.

However, another £77 million of savings will come through increased care charges paid by disabled and older people, and a further £113 million through councils cutting services. The ADASS report shows that the total £890 million reduction in the adult social care budget for 2012-13 follows the £1 billion that was lost last year.

Clarification is needed on what the government will do to ensure adequate provision of social care and support for disabled people across the country to counteract the spending cuts, increased charges and the closure of the ILF.

## **Implementing Article 19 – the Right of Disabled People to Independent Living**

The Joint Committee of Human Rights, chaired by Dr Hywel Francis MP, was conducting an [inquiry](#) into the implementation of the right to independent living for disabled people, as guaranteed by Article 19 of the UN Convention on the Rights of Persons with Disabilities (2006).

The Committee invited interested persons and groups to submit evidence on this issue and written submissions was to be submitted by Friday 29th April 2011.

Disabled People’s Organisations have long argued that the closure of the ILF would have severe consequences for many Disabled People who may rely upon ILF monies to top up the support provided through Direct Payments. Furthermore that, by their own admission, Local Authorities (via ADASS) will struggle if not fail to integrate the requirements of independent living through their broader agendas and strategies based upon the fact that that they "simply have not got the money to make

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<sup>4</sup> Report available at:

<http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&ved=0CDIQFjAC&url=http%3A%2F%2Fwww.hsj.co.uk%2FJournals%2F2012%2F06%2F13%2Fp%2Fs%2Fa%2FADASS-Budget-Survey-2012.doc&ei=baw8UNuZJcbN0QW6jICYBA&usg=AFQjCNEP7TX0aYawP8FDmLtl ISVphW7Gg&sig2=JvRgGqt610o8nrypwhelaQ&cad=rja>

up the shortfall". This problem is further evidenced by the following statement provided to the Human Rights Joint Committee<sup>5</sup>:

*...the closure of the Fund was having "an adverse impact". In evidence to us they said that "we are already experiencing people coming to us in adult social care who previously would clearly have gone to the Independent Living Fund" and that "with the majority of authorities having eligibility criteria of substantial or critical, there is little doubt that there will be many people who cannot now be assisted in the way that the Independent Living Fund was able to assist people"*

What is of great concern is that the ILF responsibilities and monies will be devolved to, and then subsumed by Local Authority Adult Social Care Budgets. Whilst it can be argued that ring-fencing is a barrier to seamless integration and provision of services, failure to safeguard and meet identified needs and outcomes will lead to a complete failure by the United Kingdom to meet its international obligations to fully implement the right contained within Article 19 of the UNCRPD [2006]<sup>6</sup>.

## **Conclusion**

The announcement of the intention to close the Independent Living Fund by 2015 goes directly against the Government's pledge to help the most vulnerable in society. It appears that the government is hoping that Disabled People do not have a strong enough voice to oppose this plan. It appears on the face of it to be a cost cutting exercise that lacks strategic planning and foresight without ring fenced replacement funding. Closure of the ILF will adversely affect the quality of the lives of thousands of severely disabled people and their families.

It is likely that more people will be forced into care because of closure, which will be more cost prohibitive in the long term. It can be said that the closure of the ILF means that severely disabled people will be left without the money needed to provide for a more independent life, a life that costs more to sustain because of complex needs that are no fault of their own.

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<sup>5</sup> HRJC – 23<sup>rd</sup> Report - Implementation of the Right of Disabled People to Independent Living

### **<sup>6</sup> Article 19 - Living independently and being included in the community**

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

People in receipt of these payments have been assessed by ILF assessors and Social Workers as being in need of this level of funding to provide for the care they need. Any needs which have been identified and assessed will still exist and are likely to become unmet, leaving many disabled people without the vital support they need to maintain independence, dignity and a quality of life.

Thurrock Coalition – October 2012

[www.thurrockcoalition.co.uk](http://www.thurrockcoalition.co.uk)