

## **Independent Living Fund letter**

Thousands of disabled people rely on funding from the Independent Living Fund and have been left shocked and extremely anxious since it was announced in 2010 that it would be closed down by government in 2015. Already it is closed to new applicants with no mechanisms in place to monitor the impact of this on the lives of those who would previously have qualified for such funding.

*The Independent Living Fund is a ring fenced resource, for a priority group of disabled people with high support needs that can provide a better lifestyle and outcomes for service users whose full needs would not be met by local authority funding.*

The LA's have had their resources severely reduced and therefore now only provide basic personal care. Without this extra funding ILF user's only options will be placement in residential care or more responsibilities on already over stretched family carers, that's if the disabled person has family support. Either option will have huge cost implications to government as residential care costs far more than assisting a disabled person to stay in the community and family carers would have to leave employment and manage on very low Carers Allowance and other benefits.

Since 2010 the Minister for Disabled people, Maria Miller, has assured users we would be consulted with initially in 2010 then delayed to early 2011, but **we have heard nothing since**.

Leaving severely disabled people in such anxiety over their lives is violating our human rights to be involved in decisions that may affect us and indicates a total ignorance of how important this funding is for severely disabled people to live with some quality of life.

The United Nations Convention on the Rights of Persons with Disabilities and in particular;

**Article 19: "Living independently and being included in the community", states that "disabled people have a right to live in the community; with the support they need and can make choices like other people do".**

**It also says they should be included in things that other people in the community do.** Countries, like the UK, who agree to the rights, have to make this happen. Two of the things they must do are:

**Make sure that disabled people get the help they need to live in the community, this means things like getting personal assistance**

**Make sure that disabled people can choose to do things in the community along with other people**

**Article 4 states; the general obligation on government to consult with disabled people, before not after decisions or policies are changed.**

**Article 17 states; we are to be treated with inherent dignity**

**Article 15; we are to have freedom from degrading treatment**

In addition, the United Nations International Covenant on Economic, Social and Cultural Rights (CESCR) states that **we have the right to enjoy the highest attainable standard of physical and mental health and the right to an adequate standard of living.**

The UK has a duty to work progressively, to the maximum extent of its available resources, to deliver these rights even in a period of economic downturn.

The changes in the ILF priority system have obvious implications for the UK's chances of meeting all such obligations, in terms of the resources available to do so as well as in the actual delivery of them e.g. ILF offers disabled people the flexibility to "choose to do things in the community".

We have heard ministers state that funding disabled people is 'unsustainable' yet we see millions of pounds 'found' to fund whatever programs the government finds politically appropriate yet not severely disabled people?

**We ask that the government continues to provide care and support for those with the most complex needs via the ILF.**

**The Independent Living Fund must be retained and reopened to new applicants with adequate funding for this.**

**It should not be restricted to only those in employment as this means those who cannot sustain paid work, but can contribute to society in others ways, will be unable to participate in their communities, families or faith activities.**

**The funding must NOT be given to local authorities; it is meant to meet the needs of severely disabled people which means that there may be more in one region compared to another. Also the LA will use the funding as they wish, it will not be ring fenced, and we suspect it will not be directed appropriately for the particular disabled people it is meant for.**

**We wish to have input into the design of the consultation process and assurances that the 20,000 already in receipt of ILF will be assured of continued funding.**

**We the undersigned believe this lack of information, consultation and arbitrary decision to close the ILF without replacing this with**

**appropriate ring fenced funding from elsewhere violates the Human Rights of disabled people who depend on ILF to live.**

**Anne Novis MBE, ILF user  
Andrew Hardy, ILF user  
Sue Elsegood – ILF user  
Katherine Arienello – ILF user  
Glynis Dawes – ILF user  
Kevin Caulfield – ILF user  
Gabrielle Pepper – ILF user  
Ruth Bashall – ILF user**

**Jaspal Dhani CEO - United Kingdom Disabled peoples Council - UKDPC  
Anne Pridmore – ILF user and director ‘Being the Boss’  
Sheila Blair – ‘Being the Boss’  
Theo Blackmore – Disability Cornwall and Isles of Scilly  
Kaliya Franklin – Broken of Britain  
Kisrten Hearne - Chair ‘Inclusion London’  
Tracey Liazard - CEO ‘Inclusion London’  
Theo Harris – CEO ‘Kensington Centre for Independent Living’  
HAFCAC - Hammersmith and Fulham Coalition against community care cuts  
Mary Cox – Age UK**

**Judith Bond  
Gemma Novis – Carer  
Fred Williams – excluded from ILF**

**Jon Staley – Support Worker & Trainer**

### **Cases that give examples of impact of losing or not getting ILF**

**A – 55 year old lady has 35 hrs allocated from LA and 36 hrs from ILF per week, if she loses the ILF and the LA does not find funds to continue support**

she will lose the following aspects of her life; Volunteering, faith activities, visiting grandchildren, unable to get out of home, do her own shopping, no social activities, trapped. She was awarded an MBE by the Queen this year 2011 for her initiatives raising awareness of disability hate crime and helping disabled peoples organisations, all such activities will cease with no ILF funding. She feels her life will have no purpose if she loses the support ILF gives.

**B** – “My Son's care package comes to over £50,000 per year of which the ILF package makes up over £23,000. The Local Authorities "Indicative Budget" maximum level for someone living at home is £31,094 so without ILF his total care package would be slashed by almost 50% and leave it impossible for him to manage to live at home”.

**C** - 25 year old man with ILF funding has been able to live independently for 7 years and get a 2:1 in Politics and International Relations plus an MA with merit in Journalism. As part of his degree course he spent almost a year working unpaid as a senior researcher for an MP. He has also worked on a self-employed basis and is now working in the media industry, in spite of being placed in the Support group for ESA previously due to his physical limitations. Without ILF funding none of this would have been possible and he would not be contributing to the economy as he is now doing. He would never have had the chance to go to university like his peers and would no doubt instead be incarcerated and abandoned by society in a residential care home costing the taxpayer much more.

**D** - “As half my care package is ILF I would first have no control over my toilet needs, this may result in me being catheterised. I am not unable to get out of bed or in bed myself, nor can I dress myself. I need support in all personal care needs, including keeping clean etc. I would not be able to attend any meetings when various government and NGOs ask me to be part of their various consultation plans. I would have no control over what time I got up or what time I went to bed therefore I would have no social life whatsoever. When ILF finishes in 2015 I will not have any social life. This will mean I will not be able to visit friends, attend the cinema or theatre, go to my bridge club or attend a primary school to assist children to read. I will no longer be able to use my car for shopping taking my dog to the woods etc. Having campaigned for the last 26 years this will end as I need support to do this. I regularly attend course on photography and employment issues – these will not be possible without ILF funding.”

**E**. “I am 27 years old female, and I currently live in my own flat, with 24 hour PA's who I have directly employed. I have had various levels of funding from ILF, ever since becoming an adult. It has meant that I was able to live on campus at the University of Warwick, where I completed a BA in History and an MA in Modern British History. I was then forced to move back to my family home, because I did not have the high level of support that I need, and I have only recently been able to start living independently in the community, with funding from my local authority and ILF. This amount was not as much as would have

previously been the case because a freeze was put on the amount that they, ILF, could contribute to disabled people's care packages in April last year, before my current care package was agreed. As a result, I was only entitled to receive the same level of funding that I had been awarded in my previous, much less expensive, care package. This meant that my local authority was put under increased pressure to fund my entire care package, and after the ILF is abolished, it seems very likely that all local authorities will find it difficult to provide care for severely disabled people living in the community. I have had to really fight against my local County Council in order to get funding for my current care package, but what scares me is that although I will always be disabled (and actually, my needs will increase in time), there is no kind of guarantee that I will receive my current care package even past my next review. "

**F.** I am a 44 year old digital artist/editor & film maker, a lot of time is spent travelling to locations for shoots, I can't imagine how I would manage without ILF which funds a third of my care package.. to lose such vital funding will probably change my life in a way presently I do not want to think about, however, as the government is pushing this legislation through regardless, I have to consider my position. Ultimately I fear that any real & significant control in my life and how I presently choose to live my life will be significantly curtailed. I know in this present political climate, any changes will be presented to the general public in a way that suggests no "significant" change, "the disabled" are worrying needlessly etc, but the reality has to be heard. I will have to make my PA's redundant, relying on goodwill of friends or volunteers would not be feasible. I would lose control of my life.