

Consultation response



Response to public consultation on the future of the Independent Living Fund

10 October 2012

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 the experiences and views of disabled people across Lothian and users of LCIIL services. For more information visit our website: www.lothiancil.org.uk

1. On the consultation process

- 1.1 Although we value the opportunity to respond to this consultation we are extremely concerned about the nature and narrow scope of it. Particularly in relation to huge changes in the welfare system, the reduction of health and social care budgets, and increasing demographic needs. The combination of these will have long lasting and negative impacts on the well-being of disabled people and people with long term conditions. In light of this the full impact of the closure of the ILF is very difficult to measure. Such a drastic move will have a significant negative effect on the lives and well-being of many individuals and **should therefore be discussed in the wider context of a proper review of social care, how it is valued in our society, and how it should be funded.**
- 1.2 *"It makes me feel like being sub-human"* said one of LCIIL's service users, while every other disabled person in the room agreed with her. In a recent event about the consultation participants, already worried about losing their quality of life and things that non-disabled people take for granted, expressed their deep fear of being seen as worthless and a burden to a society which would not recognize them any longer as human beings or equal participants in it. Are the aims of the ILF, and the outcomes it seeks to achieve, no longer valued by our society? Are well-being and a decent life no longer a right for disabled people? Or as we are told as a society, can we no longer 'afford' disabled people and people with long term conditions to live a decent life and be independent as other members of our society are?
- 1.3 Given the catastrophic consequences the closure of the ILF would cause for disabled people and people with long term conditions i.e. the sudden acceptance that they are no longer worth living independent lives and being

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more equal participants in our society, we find the approach to the consultation quite disingenuous. The ILF must have thousand of stories, facts and data demonstrating the value of its input in the lives of so many people and how it makes a difference to them. Particularly in terms of enabling a decent quality of life, rather than being a second class citizen. Why not starting with this before asking any of the questions below?

1.4 The consultation does not present any valid reasons for stopping a very successful and effective way to enable disabled people and people with long term conditions to live independent lives and remain equal citizens in their communities.

1.5 Finally the consultation does not suggest any alternative to closing the life-line of many individuals.

2. Question 1 - Do you agree with the Government's proposal that the care and support needs of current ILF users should be met within the mainstream care and support system, with funding devolved to local government in England and the devolved administrations in Scotland and Wales? This would mean the closure of the ILF in 2015.

2.1 We strongly disagree

2.2 ILF as it exists is very effective, straightforward to work with, flexible and responsive to the varied needs of individuals. For whatever reason, they do not have the stigma of social workers and have, in general a good relationships with the people they support.

2.3 Most importantly, with a central and accountable system to distribute funds they have a single set of transparent eligibility criteria, charging policy, including assessment and monitoring processes. Something of great value to disabled people

3. Question 2 - What are the key challenges that ILF users would face in moving from joint ILF/Local Authority to sole Local Authority funding of their care and support needs? How can any impacts be mitigated?

3.1 *"If money is taken away it will have to go to social work to get funds for mainstream services."* (disabled person). *"Local authorities have different policies. At least with ILF there was one policy across Scotland"* (carer). As an organisation it is also our experience that local authorities, already struggling to provide minimum support to a reducing group of eligible people,

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will divert money to a different purpose other than the ILF one. In addition to this they are not as effective, or in a position to deliver the same service as ILF, as they simply do not have the structure and processes in place to achieve this.

- 3.2 Unlike local authorities, the emphasis of ILF on Independent Living means that the funds are made available to disabled people and people with long term conditions for the very purpose of living more independent lives and tackling many of the barriers they face in everyday life. Accessing this type of support means that people are in a position to exercise their rights and duties as citizens and be equal participants in society. As stipulated in Article 19 of the UNCRPD *'disabled people have a right to live in the community, with the support they need and can make choices like other people do'*. Without a designated ILF for this purpose i.e. Independent Living, or if merging it with the bureaucratic and ineffective process of local authorities, disabled people will be denied the means to have equal access to opportunities in mainstream society.
- 3.3 In Scotland, thanks to the concordat between Scottish Government and local authorities, local authorities are no longer ring-fencing funds for specific groups or items of expenditure. In 2007, disabled people paid the price after Scottish Government monies given to local authorities for disabled people and their organisations, were never seen by them or indeed accounted for. If ILF funding is delegated to local authorities it is not just the end of ILF, it is the end of funding for independent living for disabled people and people with long term conditions.
- 3.4 If the management of current ILF funds were to be managed by local authorities these will join the current post lottery which disabled people currently experience. Within a single local authority, practice, criteria and allocations can vary depending on the individual social worker or care manager in charge of a particular individual while, at Scotland level, local authorities have different priorities, budgets and policies to allocate their funds. The consistency of the current ILF is again something that disabled people and people with long term conditions value.
- 3.5 For all the reasons above a change of ILF must be considered in the context of a wider and adequate review of future funding of social care.

4. Question 3 - What impact would the closure of the ILF have on Local Authorities and the provision of care and support services more widely? How could any impacts be mitigated?

- 4.1 In Scotland this would happen at a time when local authorities are already struggling to manage the many changes brought by the SDS Bill, are seeing their social care budgets seriously cut and their staff coming to terms, or not, with individual budgets.
- 4.2 Under such a scenario the funds allocated to Scotland will have to meet the current level of ILF allocation in the country because local authorities would not be in a position to fill the gap and it would be completely unjust and absurd to make disabled people pay the price for this. **From the experience of our organisation only, it would mean that members of our staff, volunteers and service users would no longer be able to fulfil their professional or volunteering commitments or simply live an ordinary life as most non-disabled people do.**

5. Question 4 – What are the specific challenges in relation to Group 1 users? How can the Government ensure this group are able to access the full range of local authority care and support services for which they are eligible

- 5.1 We are quite appalled by this question which suggests that, if ILF was closed, Group 2, because they have a minimum of £200/week contributed by the local authority, would be in a better position than some in Group 1, who receive ILF fund only. It is disingenuous as it misleads consultation respondents to think that eligibility for support services is the same as funding packages from local authorities. ILF was precisely set up in recognition of local authorities only funding the bare minimum for eligible individuals and that complementary funds were necessary to provide a decent quality of life rather than ensure the survival of a minority group.
- 5.2 Whether people are in Group 1 or in Group 2 the closure of ILF will for the majority of its recipients, restrict their participation as an equal member of society, entitled to, like non-disabled people, the opportunity to work, volunteer, have a social life, be independent from their family and make choices on the same basis as others.
- 5.3 If the closure of the ILF goes ahead for current members, as it did in 2010 for new social care/support recipients, it will bring about a disastrous

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situation, whereby people living , in one of the richest countries in the world, in the 21st Century, are denied their human rights, genuine citizenship and equal opportunity to a decent life on grounds of ‘economic arguments’, even though no particular reasons were ever given. This message is of very grave concern to our organisation and **such a decision should be considered and scrutinised against the apparent commitment of the UK Government to Independent Living and equal opportunities for disabled people and people with long term conditions.**

6. Question 5 – How can DWP, the ILF and local authorities’ best continue to work with ILF users between now and 2015? How can the ILF best work with individual local authorities if the decision to close the ILF is taken?

6.1 Our service users and our user-led organisation oppose the closure of the ILF as it would mean the end of Independent Living for most of its members. At present ILF is the best and most effective way to enable disabled people to live independent lives and be equal citizens in society.

6.2 We cannot imagine that across the UK any disabled person, their families, carers and other supporters, including professionals, would agree with such a proposition. We therefore would like to see the full and transparent result of this consultation.

6.3 Any further decision will have to be given with a full explanation of its rationale and implications for all.

6.4 *“ILF is a key component of my son’s package including living independently. Without it he would be made very vulnerable”* (carer of an adult disabled person). *“What changed that people would no longer need ILF to live decent lives?”*

For any questions or feedback on this document please contact:

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