

The Future of the Independent Living Fund (ILF)

Response from Cheshire Centre for Independent Living

October 2012

Introduction

Cheshire Centre for Independent Living (CCIL) is a user led organisation of disabled people based in Cheshire. Formed in 1992, CCIL offers a range of advice and information services to local disabled people (and their families) modelled along the lines of a traditional 'Centre for Independent/Integrated/Inclusive Living'

CCIL gives advice and support to people operating their own care through a Personal Budget/Personal Health Budget, and also offers a Payroll service, Managed Bank Account service, Training for Employers and their Employees, Advocacy, Peer Support, and the facilitation of mainstream activities for disabled children and short term breaks for their parents.

CCIL's mission statement is:

“Cheshire Centre for Independent Living is a user-led organisation, providing a range of support services, driven by the needs and aspirations of disabled people. Our aim is to empower disabled people to direct their own care and to promote greater independence, choice and control over their lives.”

The work of CCIL is framed by the philosophy of the Social Model of Disability and believes that disabled people are prevented from full participation within society by the way in which our society is currently structured. Although an individual may have a particular impairment or condition, it is the subsequent barriers that are present in the built environment, the attitudes of society, and the way society operates (e.g. the lack of provision of accessible information, the lack of flexibility in the working environment) that disables a person.

ILF Consultation Process

In order to obtain the views contained within this consultation response, CCIL carried out an online survey with people who use their services. CCIL also had a presence at ILF consultation events in both Wrexham and Manchester in August 2012.

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.”

When CCIL consulted with people who use its services, there was uniform agreement that this change should not happen. The fear was that the money, once it is given to Local Authorities (LA), will not go to the people who are currently receiving ILF. Some of the comments from our survey were:

“No as this money will just go into a pot and the ILF users will not see any of it as it will get lost with other expenditure.”

“Would the money that is given to the local councils reach the end user?”

“No, I suspect that the councils would not play fair with the monies.”

“My concern...is that it will be a postcode lottery for care services.”

People also feel that the ILF works well, and that if it is working, it shouldn’t be changed.

The major concern that CCIL has with the potential abolition of the ILF is whether the funding that people currently receive would continue. If there is no guarantee that the funding would be ringfenced if it was devolved to LAs, then there is a real fear that support for disabled people will be cut. The ILF also enables people portability with their care, which could be lost if it is devolved to LAs.

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?”

Once again, in CCIL’s survey, the fear was that one of the key challenges would involve cuts to care packages. We were told that:

“if local council only support then the money will either be lost or cut dramatically.”

There were also concerns raised about the knowledge and expertise at Local Authority level:

“Our experience is that local council is not responsive to the needs of the end user.”

“Local Councils don't have the understanding of what resources are needed and the individual planning of care and support.”

We also received comments about the perceived fairness of the care system when there is no nationwide system:

“I genuinely believe that input from ILF ensures a fairer hearing for us.”

“Local council would be sole decision maker. Council decision is not politically independent and can affect other areas of disabled person's life.”

The ILF has played an important role in the ability of users to live their lives independently within the community, and to enable access to activities that improve people’s quality of life. With ever tightening criteria within LA’s, it is a concern that some of these benefits would be lost.

If the ILF were to close, CCIL feels the ILF would have to work closely with Local Authorities to ensure any potential impacts are mitigated.

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?”

In the responses CCIL received, there were concerns over how Local Authorities would cope with both the increased costs and the increased workload on Local Authority workers:

“Local Councils would be under pressure and unable to cope. Care and Support services would suffer which is not acceptable for those in need of these services.”

“Local councils already struggling to cope with demand and need for services due to budget cuts and low staff resources and morale. The closure of ILF will make it more difficult for them to manage and there is a higher likelihood of mistakes being made.”

Once again, it would seem that the main concern about the closure of the ILF is centred on the role of a Local Authority, and more specifically in relation to this question, their ability to cope with the extra work. A possible solution to this could be to look at the role of Disabled People’s user led organisations (DPULO) in supporting people currently getting ILF, and utilising their knowledge and experience to disseminate information to local people, and to increase involvement by local disabled people in decision making processes.

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?”

There was a general feeling in the responses CCIL received that reflected the position of not closing the ILF:

“Keeping it as it is now and not changing it at all.”

“Don't get rid of the ILF.”

There were also suggestions that LAs would need to look at why people don't currently receive funding from them:

“Revise the system to make more people eligible.”

“LA must talk to ILF to embrace shortfalls that would occur.”

At the very least, it would appear that some provision has to be made for people who currently don't receive a service from Local Authorities, and the Government should recognise the important role DPULOs play in information giving and advice to disabled people. There is a risk that people not receiving a service from LAs will be lost in the system.

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?”

The importance of the ILF keeping people who use their service informed is an extremely important one. CCIL were told:

“They need to communicate personally with each user, not just ticking boxes and filling in forms. Each person has to be treated as an individual with their own individual needs.”

It was also felt that keeping all parties involved in what is going on is important.

“Have focus groups including all parties.”

“Share knowledge.”

There was concern however, over how LAs and the ILF would work together:

“Working together is highly unlikely without funding being made available specifically for this purpose.”

Ultimately however, it may be the case that with good planning, any changes can be seamless:

“have plans in place ready to take over so users notice little or no difference.”

CCIL feels that whatever the outcome of the present consultation on the future of the ILF, the voice of disabled people needs to be listened to, and any decisions made about the future of their care must be done with their involvement.

Wider Implications

Over the last 20 years, there have been frequent calls for a national system of assessment for disabled people's care needs, in order to avoid local variations in Social Care eligibility criteria and local differences in implementation of Personal Budgets/Direct Payments (Barnes 2007, Morris 2012). This often leads to the often quoted 'Postcode Lottery'. By removing the provision of a national system of funding for care, there is a risk of both uneven provision, and a perceived lack of fairness. From our survey, we were told:

“Disabled care should be nationwide policy and provision, not at the budgetary discretion of individuals on a council.”

It would seem that the abolition of the ILF is a negative development, when perhaps, this is the time to properly look at the implementation of a national care system.

Conclusion

People generally feel that the support they receive from the ILF is valuable, and would be greatly missed. No one who has responded to the CCIL survey wants the ILF to close, and in addition, there was universal opposition to the proposal to devolve funding to Local Authorities. The volume of opposition to this, from people who receive ILF funding, should make the Government seriously think about whether abolishing the ILF is a way forward for funding of care in the future.

References

Barnes, Colin (2004): Independent Living, Politics and Implications (accessed via internet, 28th September 2012, “The Disability Archive UK”, Leeds University Centre for Disability Studies www.disability-archive.leeds.ac.uk)

Morris, Jenny (2012): Defending the Independent Living Fund (accessed via internet, 28th September 2012, <http://jennymorrisnet.blogspot.co.uk>)