

Future of the Independent Living Fund

October 2012

1. About Carers Northern Ireland

- 1.1 Carers Northern Ireland represents the 207,000 carers in Northern Ireland who provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers give so much to society, yet as a consequence of caring, they experience ill health, poverty and discrimination. Carers Northern Ireland is a charity that seeks to improve carers' lives.

2. Background

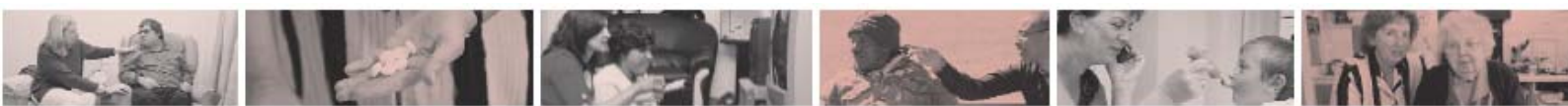
- 2.1 We welcome the opportunity to respond to this consultation as we believe the Independent Living Fund is a lifeline for people with the most severe disabilities. The Fund helps disabled people maintain their independence and alleviates some of the pressure on family members who would otherwise struggle to cope with the expense and intensity of their caring roles.

3. Flexibility, control and security

- 3.1 If the Independent Living Fund closes it will be difficult for disabled people and carers to find the same level of flexibility and control they currently have. Health and Social Care Trusts with their limited budgets and staff capacity are restricted in the services they can offer and may not be able to provide the expert care that disabled people can purchase at present through the ILF.
- 3.2 All people who depend on social care need reliable services and people with the most complex disabilities in particular need to feel secure about the level of support they can call on. The ILF enables disabled people with the highest support needs to have real choice and control over their lives and, in doing so, participate fully in society. People are naturally fearful of the loss of support.

4. Knock on impact for carers

- 4.1 Closure of the Independent Living Fund risks a serious impact on carers.
- 4.2 Caring often means families face a lower income as caring and ill-health or disability reduce families' ability to work. This is often compounded by higher costs from additional household and living expenses associated with ill-health and disability (including extra heating, laundry and transport costs). Any loss of funding from ILF would only increase the pressure on carers.



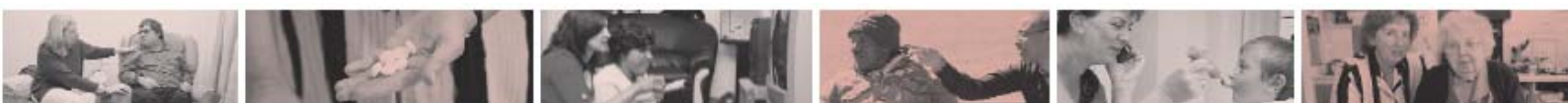
- 4.3 Two thirds of carers already use their own incomes to pay for care for the people they look after. Carers UK's Cost of Caring report in 2011 showed that, to cover the costs of care, most carers (62%) end up spending their own income, or using their savings to pay for care for the person they care for. Additionally to make ends meet, almost half of carers (45%) reported that they were cutting back on essentials like heating and food in order to make ends meet.
- 4.4 Struggling to cope with the costs of caring, many carers face debt and money worries. Around three-quarters struggled to pay essential bills (74%) or could not afford repairs to their house (78%). Half of all respondents were cutting back on food just to make ends meet (52%), and 32% of those paying rent or a mortgage say they cannot afford to pay it. 4 out of 10 carers had been in debt as a result of caring - this figure was higher with carers who were caring for children (50%) or with someone with a mental health condition (57%). The stress of debt and other money worries affected nearly half (47%) of all carers surveyed.
- 4.5 Caring also takes a toll on carers' physical and mental health. A survey for Carers Week 2012 showed that the overwhelming majority of carers (83%) say that caring has had a negative effect on their physical health, including injuries as a result of manual handling; and 87% say that caring has had a negative impact on their mental health, including stress and depression.
- 4.6 This impact is often exacerbated by carers being unable to find time for medical check-ups or treatment, with two in five carers saying that they were forced to put off treatment because of their caring responsibilities – unable to trust or find suitable and affordable replacement care.
- 4.7 This data reinforces analysis of population-wide data from the 2001 Census data, which showed that those caring for 50 hours a week or more are twice as likely to be in poor health as non-carers.
- 4.8 This demonstrates the importance of the Independent Living Fund to carers, as it enables disabled people to pay for specialist support which greatly assists carers' ability to look after them, offering the chance of a break from their caring role. Loss of funding through ILF would be catastrophic for carers who are already struggling to look after loved ones with a serious long-term condition or disability.

5. Consultation Questions

5.1 Question 1

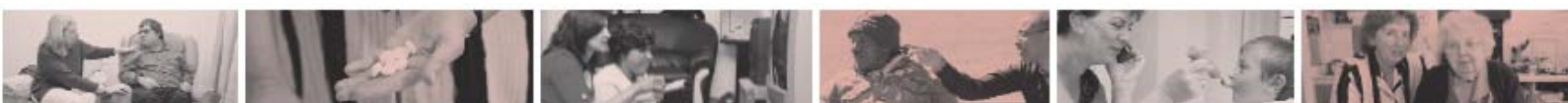
Do you agree with the Government's proposal that the care and support needs of current ILF users should be met within the mainstream care and support system, with funding devolved to local government in England and the devolved administrations in Scotland and Wales? This would mean the closure of the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

- 5.2 We are concerned that the government has only put forward one option in this consultation ie to close the ILF and pass ILF responsibilities to the devolved administration in Northern



Ireland. The consultation does not set out any detail as to how this responsibility will be delivered.

- 5.3 There are many questions that remain unanswered. For example, will each Health and Social Care Trust be given be a ringfenced budget to fund current ILF recipients? Will there be an equivalent assessment of need for future beneficiaries of such funding? Will funding to individuals be withdrawn and replaced by 'services', removing disabled people's choice and independence?
- 5.4 **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?
- 5.5 Disabled people and their carers will face the loss of independence, choice and control if funding is solely provided Health and Social Care Trusts. Care provision is inconsistent across the Trusts in Northern Ireland and all of them are under severe budget pressure. Trusts are already beginning to limit their funding to the people with the highest care needs. Having to fund people moving from ILF will only increase the pressure on budgets and will have an impact on other disabled people and carers.
- 5.6 The ILF offers a needs-led rather than budget-led independent approach to support. It also offers portability of support packages without reassessment, allowing people to move to another area, taking their care package with them. Mainstream funding is unlikely to offer this.
- 5.7 Without additional ringfenced funding to maintain ILF users' support packages there is a real fear of two stark alternatives for disabled people: staying at home without adequate support, putting their own health and wellbeing at risk, or moving into residential care. Carers, who already dip into their own funds to provide care will be in an impossible situation – either needing to give up work altogether to provide additional care or needing to find even more money to buy in additional support.
- 5.8 **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?
- 5.9 Health and Social Care in Northern Ireland is currently under review, with the implementation of the recommendations of *Transforming Your Care*. This review seeks to place an emphasis on personalisation and the delivery of care within people's own homes rather than in a residential setting. It is not clear how the care of ILF recipients will be integrated in this new model and it looks set to provide a further complication for health and social care delivery in Northern Ireland.
- 5.10 These Health and Social Care reforms seem destined to place an even greater demand on family carers and the additional impact of the loss of ILF for those with very high care needs



to be taken into account. Support for carers in the form of short breaks and respite, health checks and training in practical care skills will all need to be provided for this to work.

5.11 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?

- 5.12 Older disabled people will be most affected by the closure of the Fund and therefore most at risk of admission to a care home if the local authority is unable to provide adequate care and there is limited family support. Government needs to ensure that this group continues to receive a full needs assessment with services provided in response to those needs rather than by limitations of budget. Again we need to ensure that any carers are fully supported to look after people who may lose out following the withdrawal of ILF funding.

5.13 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?

- 5.14 Disabled people, carers and their representative organisations should all be represented on any working party/committee, which produces proposals on the back of the consultation. We can make available a copy of our good practice guide on involving and consulting carers.

6. Final comments

- 6.1 Despite contributing an estimated £4.4 billion to the Northern Ireland economy with the unpaid care they provide, the vast majority of people are worse off financially as a result of becoming carers. This is because of the combined pressure of low-level benefits, reduced earnings and higher living costs resulting from illness and disability. Without the support of the Independent Living Fund many carers simply could not afford to pay for the additional care needs of their severely disabled family members, with the likelihood of their loved ones losing their independence and having to go into residential care.
- 6.2 We strongly urge Government to rethink the proposal to close the ILF as we have serious concerns about the impact of changes and their potential to result in a diminution of support to disabled people, as well as the knock on impact on their carers and families. We need reassurance that funding or services will be provided through health and social services to avoid the negative impact on carers of having to fill any gap in care.

For more information or to discuss this response please contact:

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