

Housing Learning & Improvement Network

Care Services Improvement Partnership 

Health and Social Care
Change Agent Team

Independent Living: the future

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The authors were commissioned by the government to review the **Independent Living Fund** which was the first cash-for-care vehicle. In this article, they present the case for radical change based on their findings.

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The future of social care, according to repeated Ministerial statements, lies in the personalisation of support and the development of choice and control. This was a core message of the 2006 White Paper *Our Health, Our Care, Our Say*, as well as a key concept behind the 2005 Prime Minister's Strategy Unit report *Improving the Life Chances of Disabled People*, and the subsequent establishment of the Office for Disability Issues (ODI). Central to the model is the further promotion of Direct Payments, and the piloting of Individual Budgets (IBs). Empowering service users through the provision of cash rather than direct care seems to be the next big idea - Ivan Lewis, the Minister for social care went so far as to tell delegates at the National Children's and Adult Services Conference last October that IBs are not just experimental, but provide the foundation stone of a modern social care system.

The evaluation of IBs is on-going and it is too soon to call the results, but expectations are high that the model will be rolled out from 2010. Even if the evaluation were to find that IBs are not cost neutral, or that there were other impediments to the model being widely adopted, it is almost impossible to imagine that something similar to IBs will not take hold. The genie is out of the bottle: service users who have experienced the freedoms and flexibilities of being able to make their own choices are not going to accept anything less in the future.

'Cash for care' may be the latest bit of social care jargon, but the concept behind it is nothing new. The first such model – the Independent Living Fund (ILF) – was established almost 20 years ago. We have completed an independent review of the ILF, on behalf of the Department for Work and Pensions (DWP), to consider how the ILF fits within the new IB world.¹

¹ Henwood M and Hudson B (2007), *Review of the Independent Living Funds*, Department for Work and Pensions.

As with many developments in social care policy, the ILF originated and grew incrementally. It was established in 1988 as a result of the changes in the social security system which saw the introduction of Income Support. Unlike the former Supplementary Benefit system the new simplified model of support did not feature domestic assistance allowances that had enabled Supplementary Benefit to support severely disabled people who chose to live at home rather than in residential accommodation. Transitional arrangements were established to protect the 300 or so people who could lose out, and more permanent arrangements for people needing such help in the future were created by the establishment of the Independent Living Fund. Originally given a lifespan of 5 years, the ILF soon attracted more claims than predicted and by 1993 was supporting 23,000 people. The Government made a commitment to maintaining a fund to support this group of people and since 1993 two Independent Living Funds have operated (one – the Extension Fund - for existing clients prior to 31st March 1993, and the other – the 1993 Fund - open to new claims).

Today the ILF supports more than 18,000 people, at an annual cost of almost £264 millions. We recognise that for many of these people the ILF is highly valued. The review collected evidence from many service users and their families who praised the ILF and highlighted its life changing impact. The comments reproduced in the box below are typical of many.

The importance of the ILF to service users

“It’s a marvellous service, and opened up a whole new life for my son and us as a family.”

“I work with several adults who use ILF monies to enable them to be at home. Quite simply – no ILF, no living at home.”

“For the first time for 39 years we have been able to enjoy a normal social life.”

“The increase in life quality for me is immeasurable and I appreciate very much what the ILF makes possible for me.”

“I would like to say that life would be impossible without it. It enables me to live a relatively normal life with my wife and in my own home. Without it I would be condemned to life in a nursing home, which would be no life whatever.”

“ILF has transformed the life of my brain injured son.”

“I cannot speak too highly of the ILF service. After 50 years looking after my daughter we are now able to live our own lives knowing that she is well supported.”

It is important to acknowledge these positive findings at the outset. However, these comments typically point to the value which service users attach to support which enables them to remain in their own home, and to live the life they choose. What the comments do *not* offer is an analysis of whether such qualities are intrinsic to the operation of the ILF. We therefore needed to unpack the valued features in much greater detail by analysing the operational framework of the ILF. That framework is very complex. Whilst it is important for us to address these complexities it is also vital that we do not lose sight of the principles and values that should logically underpin such a framework. We chose to evaluate the operational framework of the ILF against the following six criteria:

- *Equity*
- *Transparency*
- *Accessibility*
- *Self-Determination*
- *Flexibility*
- *Values and Outcomes*

Analysed against these principles there is much in the operation of the ILF which is less than ideal. The ILF is a surprisingly little known scheme. One of the recurrent themes in our review was that the ILF was ‘below the radar’. Not only was it often described as ‘one of the best kept secrets’, but it became increasingly evident that the ILF is anomalous and - in many ways – anachronistic. Not only do many people not know about the existence of the ILF, but its eligibility criteria mean that access is by no means straightforward. People with very high support needs are precluded from applying to the ILF (as are those in the final stages of life) because of a spending cap in the first six months of support. Others with substantial needs also fail to get the level of support they need; people aged over 66 cannot apply to the ILF, and many others (including former residents of long stay hospitals) are either excluded from applying or limited in the support they receive.

The fact that the ILF operates in parallel to the processes operated by local authorities is also a source of problems. The ILF applies different rules around charging; uprating of payments; treatment of benefits and of occupational benefits and capital limits. For service users the result is confusion and unwanted bureaucracy in having to cope with the conflicting demands of two systems.

The cash provided by the ILF does not come without strings. This is probably the area which is most out of kilter with the development of new cash for care models. The approach pioneered by In Control and being promoted by the pilot Individual Budgets schemes takes the concept of ‘self-directed support’ to maximise freedom for people in how they use the resources available to them. By contrast the ILF can be used only to pay for ‘personal care and domestic assistance’ which can constrain the more innovative and tailored support that people want in their lives.

Many of the changes which would be needed to bring the ILF more into line with the current discourse on self-directed support are ones which the ILF has itself argued the case for. The ILF has limited autonomy and operates within the legal framework of a Trust Deed and associated conditions of grant agreement specified by the sponsoring department (DWP). The big question is whether changing that framework and bringing the ILF up to date would be sufficient. We concluded that some of the more obvious shortcomings of the rules of the ILF can – and should – be tackled. However, we believe that in the longer term more radical reform is required.

The ILF is a creature of its time. Indeed, it was ground-breaking in providing the first cash for care model. However, the new policy framework around individualisation of support (whether through individual budgets or any similar model) requires coherence and

integration of all streams of funding. It is anomalous to retain a separate Non-Departmental Public Body (NDPB) with responsibility for a large amount of social care expenditure operating in parallel to the mainstream world of independent living. Not only does this needlessly duplicate bureaucracy and administrative systems, but the idea of funds being allocated through an NDPB (part of which is a charity) sits uncomfortably with the ethos of the independent living movement in the 21st century. A preference for rights not charity, and for transparent decision making through accountable and democratic processes, is not compatible with decisions made by a Board of Trustees operating behind closed doors.

As we noted at the outset, the ILF makes an enormous difference to people's lives. It is essential that this is safeguarded and that people do not lose such valued support (or fear losing it). In the short term (through to 2009/10) we have recommended that the ILF should remain in its present form but should address many of the improvements we have indicated should be implemented. In the longer term, however, there should be a smooth transition towards full integration of the ILF within a national system of personalised budgets. The future model needs to be based upon localisation and integration, rather than centralisation and separation.

Melanie Henwood & Bob Hudson

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