Independent Living Fund – Post-closure Review

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Background
The Independent Living Fund (ILF) was a UK-wide scheme set up in 1988 to provide financial support to disabled people with high support needs and to enable individuals to live independently. The ILF was permanently closed on 30 June 2015. The responsibility for supporting ILF users in England was passed to local authorities (LAs) in line with their statutory responsibilities. The decision to close the ILF was to ensure that all social care support is delivered through the mainstream system, rather than two separate systems. The decision also took into account the significant developments in adult social care over the last 20 years since the start of the ILF.

To enable LAs to meet these responsibilities in a way that was appropriate to the local context, the transference of responsibility did not stipulate a national framework for LAs to follow, nor was there any mandatory ring-fencing of the funds. LAs therefore adopted different approaches to manage the transition. The Department for Work and Pensions (DWP) committed to monitor the impact of the closure of the ILF on former users. It is in this context that the DWP commissioned this research to investigate the closure and the effects for recipients living in England (Section 1.1).

Methods
A qualitative research design was adopted for this study (chapter 2). Depth interviews were conducted with:

• 50 former recipients of the ILF, or unpaid family carers that took part in proxy interviews on behalf of a former recipient who was unable to take part themselves due to the nature of their health condition; and

• staff working in ten different County Council or LA adult social care services divisions with responsibility for managing the ILF closure locally.

Depth interviews were used for this potentially sensitive research topic as it allowed for one-to-one discussions whereby participant’s individual narratives, views and experiences of the ILF closure could be discussed in-depth in a private and confidential setting. Furthermore, this approach gave participants greater control to cover topics of particular resonance to their unique and often complex lived experiences. Interviews took place between August and September 2016.
Local authority management of the transition

LAs adopted a localised approach to the transition unique to their area. A clear timeframe for the transition period helped LAs in managing the transition process. Appointing a dedicated delivery team seemed to facilitate a smooth transition. The inclusion of staff with prior knowledge of the ILF aided an understanding of the potential sensitivities involved.

Implementation successes included personalised and sensitive LA communications. This approach appeared to be linked to alleviating the anxieties of former recipients’ and their next of kin about the transition. In contrast, LA initial letter communications that mentioned financial constraints of the LA and/or the possible reduction to care tended to raise concerns.

Collaborative working with the ILF was felt to provide LAs with a better understanding of former recipient needs. Partnership working tended to happen between LAs and local ILF teams with an existing relationship. It may have been beneficial to have had a longer overlap period with the ILF or to have had retained staff with ILF knowledge for an extended period to support queries following the permanent closure.

The ILF transition coincided with the introduction of the Care Act 2014; LA staff and decision makers were still becoming familiar with the new eligibility criteria. Another challenge was negotiating reductions to some care packages. Face-to-face meetings with former recipients and their next of kin to sensitively discuss alternative provisions, changes and reductions to care helped to negotiate these difficult decisions.

While LA staff found it difficult to assess the overall success of the transition at this stage, the smooth money transfer from the ILF to the LA was considered a positive achievement. LA’s organisation of payments ensured that former recipients did not have gaps in funding. Levels of complaints, appeals and unscheduled reviews were also used as interim measures of success. Staff suggested that a concrete measure of success would be gained at the next scheduled care reviews which will assess whether the awarded packages of care were sufficient and identify any unintended consequences for former recipients or their next of kin.

Former recipient views and experiences of the transition

Former recipients received formal communications from the ILF informing them of the closure of the ILF. LAs had responsibility for providing information about the local transition process and what the new arrangements would be. Former recipients felt well informed about the ILF closure through clear and frequent communications from the ILF. However, satisfaction with LA communications varied, as each LA adopted their own approach. Following the announcement of the ILF closure, former recipients wanted to know what their new arrangements for care and support would be. In cases where there was an absence of any information or unclear information from LAs about the new arrangements, former recipients felt anxious about the prospect of losing the care and support previously funded by ILF (Section 4.1). This anxiety was compounded for some recipients by their knowledge that the funding transferred to LAs was not ring-fenced. Concerns centred on the prospect that reductions or changes to care and support arrangements would have direct implications to having their care needs met and ability to engage in activities that they wanted to.

LAs assessed eligible care and support needs of former ILF recipients to establish the new arrangements following the closure of the ILF (section 4.2). LAs adopted different models for the format of these assessments; while some included ILF staff, others did not. Former recipients reported feeling reassured about assessments that included ILF involvement, such as joint assessments with ILF assessors.
and LA social workers or ILF care plans being used within assessments. ILF staff were generally seen by former recipients as more experienced and understanding of recipients’ needs compared with LA social workers. This was linked to the fact that recipients tended to report having good relationships with ILF staff that they had developed over a number of years. In contrast, LA social workers tended to be unknown to recipients and could lack basic awareness about their health condition and needs. Furthermore, in the context of austerity and the closure of the ILF, former recipients perceived that LA social workers had been instructed to cut care packages to save funds.

**Former recipient views and experiences of the new arrangements**

The new LA arrangements can broadly be grouped into three categories: an improved, matched or reduced package of care, compared with the arrangements under the ILF (Section 5.1). Participants on a matched award included those undergoing an appeal, complaint process or awaiting an outcome of an LA assessment. Knowing the outcome of reassessments reduced or removed anxiety about the closure, especially if the care package had stayed the same or was better. However, a level of anxiety and uncertainty remained for those awaiting an outcome of an ongoing review, appeal or complaint. Anxiety and worry about the closure also remained for those on a reduced package.

The monetary transfer from ILF to LAs was experienced as smooth (Section 5.2.2); no major disruptions to receiving payments were reported by research participants. Former recipients had anticipated that there may be funding gaps during the transition and disruptions to accessing services and care provision but these concerns were not realised. New LA arrangements featured the use of personal budgets which provided former recipients with a flexible and person-centred method of receiving and paying for care services (Section 5.3.1). Former recipients found LA accounting procedures and spending guidelines to be more restrictive than under the ILF system.

Improved, matched and slightly reduced packages under the new arrangements enabled individuals to maintain the level of support and care they received prior to the closure. These participants retained a similar level of choice and control over their care and reported limited or no changes to their independence (Section 5.3.2).

Those with a heavily reduced package of care and support experienced multiple changes as a result including: loss of paid care and support; an increased reliance on unpaid care; and changes and restrictions to daily activities, including less support for engaging in leisure activities. Participants reported that heavy reductions in care affected some people’s physical and mental health. Participants on reduced packages reported lower trust in the social care system as a result of the changes (Section 5.3.3).

The ILF closure brought about wider concerns about the social care system (Section 5.3.4). Former recipients felt vulnerable to future reductions to funded care and support. These worries were linked to the perception that LA social services are under-resourced and have restricted budgets. Former recipient worries were compounded by the prospect of being reliant on the LA as their sole source of funding. Participants therefore anticipated that they would need to ‘fight’ to maintain the care package they need in the future. This vulnerability was experienced regardless of the current arrangements, and was felt even by those with improved and matched packages.