

## Review of the Independent Living Funds: Executive Summary

### Introduction

This is the report of a review of the Independent Living Funds (ILFs) commissioned from independent consultants, Melanie Henwood and Bob Hudson, by the Department for Work and Pensions (DWP) in June 2006. The report draws together evidence gathered from a range of sources including written submissions from individuals and organisations, consultation meetings held around the UK with ILF service users and their families; and from a programme of interviews with national stakeholders. This evidence is located in an analysis of wider policy developments in social care and independent living. Our approach is explicitly evidence-based.

The Independent Living Fund was first established in 1988 as a transitional arrangement to provide cash to support severely disabled people living at home, and who were at risk of losing the value of domestic assistance allowances provided under the old Supplementary Benefits system. The ILF proved very popular and in 1993 a commitment was made to maintaining a fund to provide support and a second ILF (the 1993 Fund) was established to receive new cases while the original fund was closed to new applications, and replaced by the Extension Fund. Since 1993 there have been two ILFs operating in parallel.

The time is right to reconsider the role and contribution of the ILF. Since 1988 there have been many changes in the wider world of social care. At the time that it was established, the ILF was unique as the first example of a 'cash for care' scheme in the UK. This is no longer the case with the arrival of Direct Payments, In Control, and – most recently – the pilot development of Individual Budgets. Moreover, the wider context for these developments is provided by a changing policy environment characterised by new ideologies of disability based around the pursuit of citizenship, participation and empowerment.

The DWP asked the consultants to consider:

- Whether the ILFs should continue to exist, and if not what should replace them?
- If they should continue, what changes might need to be made, and how could service be improved?

It is important to acknowledge at the outset that the support from the ILF is highly valued by many of those who use it. We received evidence from service users who described the difference the ILF made to their lives, and this was also a striking feature of the debate in our consultation meetings. We needed to unpack these comments and understand them in more detail and we therefore approached the review by establishing an operational framework of principles and values to guide our analysis. These are:

- equity;
- transparency;
- accessibility;
- self-determination;
- flexibility;
- values and outcomes.

These principles were not randomly selected. They were informed by the views of service users and from a wider body of research identifying the features of social care services that are highly valued. We have used the framework to analyse the operation and performance of the ILFs. Our analysis is therefore explicitly value-based as well as evidence-based.

## **OPERATIONAL FRAMEWORK**

### **Equity**

The ILF has some strengths in respect of equity principles. The UK-wide nature of the operation provides unusual national portability. However, this does not, of itself, guarantee geographical equity and we identified wide variation in take-up rates.

The total numbers of people supported via the ILFs are very small compared with the potential client population. People are also unable to access the ILF for a variety of other reasons associated with the eligibility criteria and operational rules. People with very high support needs are precluded from applying to the ILF, others are also barred from applying to the ILF or are limited in the support they receive, including people aged over 66; former residents of long stay hospitals; people with substantial support needs; some disabled people with partners; disabled people who are parents; black and minority ethnic users; people in education and learning, and people in the final stages of their life. We conclude that the ILF is characterised by an unacceptably high level of inequity that must be addressed as a matter of the utmost urgency.

### **Transparency**

It was apparent in the course of the review that people's experience of the ILF is often far from transparent. People often do not know how their money has been calculated (or how it should be); they have little knowledge of the organisation and its decision making; and they are uncertain about whether and how they can challenge those decisions.

Our evidence demonstrates that the ILF does not meet many basic expectations about the consistency of decision making, accountability for decisions, and ensuring

dignity for service users. People's experience of the ILF is highly variable and influenced by arbitrary factors, and a recurrent theme across our evidence was that the existence of the ILF is one of the 'best kept secrets.' We have accordingly made recommendations to improve advocacy and support for people using the ILF, and also to address structural and operational factors to improve the visibility and comprehensibility of the ILF's systems and processes.

## **Accessibility**

We found multiple factors which compromised the accessibility of the ILF to its users, potential users and the wider public. We have made recommendations for reforming and simplifying the eligibility criteria to improve accessibility. We have also addressed the numerous anomalies which exist between the rules of the ILF and those adopted by local authority social services departments. We do not believe it is in the interests of service users for there to be different and contradictory operating systems in respect of issues such as charging, the treatment of benefits, occupational pensions, capital limits and upratings. We have recommended that these inconsistencies are tackled urgently.

The duplication of functions between the ILF and social services is also an impediment to accessibility, and we have recommended that these are resolved by the integration of key processes of application and review.

## **Self-Determination**

Self-determination is an increasingly important concept within notions of independent living. Making choice a reality requires the development of life planning, user-led support systems, self-assessment, and resource allocation systems. Our evidence does not indicate that the ILF performs well against such criteria, particularly in comparison with the leading edge of policy and practice that is apparent elsewhere (notably in the approach of In Control).

We have recommended a series of reviews of policy and practice, and accompanying strategic development, that need to be undertaken to prepare the way forward. It is essential that such activity is undertaken in partnership with local authorities and other agencies to ensure future synergy. Just as we have recommended the integration of application and review processes, we also recommend the integration of assessment between the ILF and its partner agencies.

## **Flexibility**

There are tensions between the ILF's rules and its powers of discretion. This results in uncertainty and inconsistency for service users and their advocates. We have recommended that improvements should be made in the flexibility and responsiveness of the ILF. In particular, these have implications for the ways in which ILF money can be spent (and reviewing the restrictive definition of 'Personal

Care and Domestic Assistance'), but also for ensuring coherence with the approach of Direct Payments in respect of roll-over of funds and payment in advance. We have recommended that the ILF should recognise the support needs of ILF users as employers as a matter of policy rather than as a matter of discretion as is currently the case.

The restrictions on how ILF money can be spent do not sit comfortably with the new spirit of independent living that is being encouraged in the wake of the Improving Life Chances report from the PM's Strategy Unit. If the ILF is to play a continuing role it must sweep away increasingly anachronistic rules which limit the opportunities for people to live their lives.

## **Values and Outcomes**

The ILF originated at a time when the prevailing model of disability was a largely medical rather than social one. The ILF is aware of the changing ideological and policy environment around disability and independent living. However, it has not championed such changes or sought to be at the leading edge of development. The evidence does not indicate that the ILF has the ideological sophistication required of an organisation promoting new models of independent living.

## **STRATEGIC FRAMEWORK**

The operational framework analysis provided the heart of the review, focusing primarily on how ILF users (and potential users) experience the ILF. However, this does not tell the complete story, and the review also examined how the ILF functions strategically, and how – in turn – the strategic environment structures the operation of the ILF on a day to day basis.

The review examined four main dimensions of strategy highlighted in Cabinet Office guidelines for the reviews of NDPBs. These are: strategic links and partnerships; openness and accountability; the legal framework and corporate governance.

### **Links and Partnerships**

The ILF has a range of partners, but the most significant links are: the relationship with local authorities; the interface between ILFs and Individual Budgets; and the intersection with the NHS.

The relationship with local authorities is a recurrent theme throughout the report. The absence of synchronicity between the two agencies is often problematic, confusing and cumbersome. Improving coordination with local authorities has been a concern of the ILF, and we support the continued development of such linkages. Whether functions should ultimately be integrated rather than simply aligned is an issue on which evidence was divided, and the issues are complex. We recommend that no immediate transfer of ILF funding and remit is made to local government, but in our

conclusions we recommend that in the medium term there should be full integration with Individual Budgets.

The ILF plays a full and committed role in the development of IBs. How this might be improved is a central issue, and the early stages of development of IBs do not allow a range of options to be considered at this stage. Further synchronising of systems between the ILF and IBs should become possible with the advent of new flexibilities arising from a revised ILF Trust Deed as well as from many of the recommendations of this review where they are implemented.

The interface with the NHS raises much broader issues about the place of community health services in future IBs. This is a policy issue for the Department of Health to reappraise, but in the interim we recommend that ILF users who qualify for continuing health care should not automatically lose their ILF eligibility.

### **Openness and Accountability**

The ILF aspires to improve its consultation and to reflect on the views of service users in shaping its policy and practice. This is welcome, but the review identified considerable shortcomings in the approach to user involvement to-date. Consultation has been selective, and - in many respects – tokenistic, with inappropriate constraints placed on the role and remit of the User Group.

The limited achievements of the ILF in this area thus far indicate the need for expert advice and support in taking this agenda forwards, and we have strongly recommended the active collaboration of the ILF with a user-directed organisation to support and refine the consultation and inclusion strategy.

### **The Legal Framework**

At the time of the review the ILFs were in a state of limbo as they waited for a new Trust Deed to come into effect and a new COGA to be agreed. The new Trust Deed is contingent on Royal Assent being granted to the Welfare Reform Bill. However, if that is granted as expected, the new Deed offers a much needed and long overdue rationalisation and streamlining of the two parallel Deeds which have operated for the Extension Fund and the 1993 Fund. The new Deed also goes further than simply tidying up and consolidating the two Deeds and creates the preconditions for a more flexible and responsive ILF to develop, and removes many of the legal impediments which have previously existed. The capacity of the ILF to widen its eligibility criteria or to change the rules it applies is constrained to a large extent by the existing Trust Deed and associated Conditions of Grant Agreement set by the DWP.

The extent to which this potential will be realised will depend on the initiative and vision of the DWP, ILF Trustees and the ILF Executive Team, and steps need to be put in place immediately to demonstrate commitment to the new opportunities arising from piloting powers.

## **Corporate Governance and Reporting**

The reporting and accounting arrangements for the ILF are vested in the Department for Work and Pensions, and we have recommended that this should remain the case. However, given the complexity of issues around independent living, there is a need for interdepartmental coordination between DWP and DH, ODI and the ILF. It is important that the findings from this review are considered alongside those of the ODI Review of Independent Living and that ODI/DWP jointly take forward the future ILF agenda in the light of wider developments in respect of independent living.

There are issues which arise across Government in the various parts of the UK. We believe the momentum for individual budgets and self-directed care is replicated in all four countries and in order to maximise opportunities for independent living appropriate quadrilateral policy groups should be established.

## **CONCLUSIONS**

The review of the ILF makes four key assumptions in presenting its conclusions:

- doing nothing is not an option;
- no loss of service for ILF users and no overnight change;
- necessity of second-guessing emergent policy change;
- commitment to value based reform.

The recommendations made throughout the review point to the need for considerable changes in the rules and procedures of the ILF. However, we do not think it sufficient to 'tidy up' anomalies; the issue is to consider where and whether the ILF fits within future strategies on independent living.

In view of the considerable turbulence which surrounds policy at this time we need to consider both the immediate future and the longer term. In the interests of stability for service users we recommend that the ILF should retain NDPB status until at least 2009/10 at which point a further decision should be made in the light of wider developments, and with a presumption of full incorporation into the Individual Budgets programme.

Many of the changes recommended throughout the review are focused on the next few years. If implemented they will greatly improve the equity, transparency, accountability and accessibility of the ILF. However, these changes do not offer a medium or longer term alternative to the preferred option of a smooth transition to comprehensive integration into a national system of personalised budgets.

The ILF has played a significant part in the short history of independent living. Its achievements over the last eighteen years have been important. Under the proposals of the review the ILF will have a continuing – and growing – role over the next few years. In the longer term, however, it is anomalous to retain a separate NDPB with responsibility for a large amount of social care expenditure, operating to

different rules and remits from mainstream activities. With the anticipated move towards individual budgets such incongruence will become more pointed. The case for a separate and continuing existence for the ILF beyond the medium term is not therefore accepted.

The challenge for the ILF in the next stage of its life cycle is to be an excellent partner in the pursuit of full integration of personalised budgets. The best interests of all disabled people wishing to live independently must take precedence over any issues of organisational interest. A better chance for a good quality independent life should be the goal to unite the ILF and its partner organisations in the coming years.