

Review of the Independent Living Funds

Report by independent consultants
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Foreword and Acknowledgements

This is the report of a review of the Independent Living Funds, commissioned in June 2006 by the Department for Work and Pensions from independent consultants, Melanie Henwood and Bob Hudson. The views expressed in the document are those of the consultants, and not necessarily of the Department for Work and Pensions.

The consultants wish to thank all those who assisted with the review. In particular, we are grateful to all of those who gave generously of their time and shared their views with us; to those who took the time and trouble to submit written evidence to the review, and particularly to those ILF service users and their families who shared their experiences with us.

We would also like to acknowledge the support of the DWP in the course of the review, particularly of Sharon Foster-King and Jane Cocking.

Finally, we are grateful to all the members of the Steering Group who provided us with helpful advice: John Hughes and Bruce Calderwood (DWP); Patience Wilson (DH); Jacinda Humphry (ODI); Marta Hancock (ILF user); Margaret Cooper (Chairman of the ILF Trustees), and Elaine Morton (ILF Chief Executive).

Contents	Page
Executive Summary	i
Section 1 Introduction and Background	1
Operational Framework Section 2 Equity	26
Section 3 Transparency	42
Section 4 Accessibility	51
Section 5 Self-Determination	68
Section 6 Flexibility	82
Section 7 Values and Outcomes	96
Strategic Framework Section 8 Links and Partnerships	106
Section 9 Openness and Accountability	117
Section 10 Legal Framework	127
Section 11 Corporate Governance and Reporting	134
Section 12 The Future Organisation: Recommendations and Conclusions	141
Appendices	
Appendix 1: Review Methodology	167
Appendix 2: Feedback from Consultation Events	172
Appendix 3: Glossary of Acronyms	180

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.

Section 1: Introduction and Background

The External Review: approach and methodology

- 1.1 Independent consultants, Melanie Henwood and Bob Hudson, tendered successfully to undertake an external strategic review of the Independent Living Funds (ILFs), commissioned by the Department for Work and Pensions (DWP). The terms of reference for the review are the general ones laid out in Cabinet Office guidance for the review of Non-Departmental Public Bodies (NDPBs), i.e:
- Should the ILFs continue to exist, and if not what would replace them? (Stage 1)
 - If they should exist, to identify any required changes to the groups funded by the NDPB, policies, processes, funding level and relationships of the ILFs and how can their service be improved? (Stage 2)
- 1.2 The review began in June 2006 and was completed within six months, as required by the DWP. The consultants were employed on the basis of the review requiring 3-4 days per week throughout this period (i.e. a total of 84 days); some administrative support in arranging and handling consultation mechanisms was provided to the consultants by the DWP. An early output from the review was the production of a substantial background 'Scoping Paper' which explored the key dimensions of the context to the review, the contours of the emerging debate and highlighted some of the issues likely to emerge in the course of the review.¹ The scoping paper has informed the approach of the review as well as providing a stand-alone document to illuminate the central issues to be explored to a wider audience. We approached the review with a strongly value-based position, informed by an understanding of and commitment to the social model of disability. However, we also approached it with no preconceived notions about the possible outcomes.
- 1.3 The review is evidence-based. All of the conclusions and recommendations that we present are based firmly on the weight of evidence received. A four-stranded methodology has been followed comprising:
- Announcement of the review by DWP and an invitation to submit views (with all ILF users being informed about the review).
 - Distribution of a formal call for written evidence submissions, with a deadline of 30th September 2006.
 - Series of consultative meetings with ILF service users and their family carers.
 - Programme of one to one interviews with central government and other national level stakeholders (which took place between mid June and early December 2006).

- 1.4 With any piece of research or evaluation there comes a point where a line must be drawn in collecting data. We used the 30th September 2006 as our cut-off point, but we interpreted this flexibly and incorporated late submissions and other material that we identified after this date. Similarly, the majority of our interviews were completed by the end of September but some had to be conducted later owing to the unavailability of our witnesses earlier in the year. It remains the case that inevitably there will have been further developments, both within the ILFs and elsewhere, since we ceased collecting data and began our analysis and report drafting. However, we do not believe that substantive developments have been overlooked, and where the ILF or other organisations have developed plans or intentions in the latter part of 2006 these have not yet taken effect and do not make any of our recommendations or conclusions redundant.
- 1.5 This layered methodology enabled the consultants to build up a range of qualitative and factual evidence, to compare findings from the different components, and to assemble a rich and detailed story about the nature and experience of people using the ILFs. Additionally, we have brought to the review a wide variety of existing evidence relevant to the issues, along with our own specialist expertise in policy analysis.
- 1.6 Throughout this report of the findings from the review we will weave together the evidence from these different sources of investigation. In undertaking the consultative meetings and one to one interviews we offered participants certain assurances about the terms of their engagement. In particular, we will not use any material from these processes that will be attributed to individuals, or which allows them to be identified. We do, however, make use of anonymised material where it illuminates the points we are making. In the case of written submissions the issue of anonymity is less of an issue since most of the responses have been received from organisations or bodies which are perfectly happy to identify themselves. Where it is relevant to the report we will draw on such material and attribute it where appropriate.
- 1.7 Appendix 1 provides further detail on the different elements of the methodology. In total 385 written submissions were sent to the review (identified in this report as our 'respondents'). Of these, the majority – 212 items, or just over 55% of the total - were individual items of correspondence from ILF users and their families. The second largest group of submissions (140 items, 36.4% of the total) were formal written submissions from organisations received in response to our call for evidence. Many of these were the result of local consultation meetings and therefore reflected the views of a considerably larger constituency than the numbers might suggest. Thirty three submissions (8.6%) were received from people working in social care who were responding in a personal capacity rather than on behalf of their organisation. In addition, semi-structured interviews took place with two dozen key stakeholders (identified in this report as our 'witnesses'). Most interviews took around 1½ hours (and some were considerably longer); most were digitally recorded and fully transcribed.
- 1.8 We were eager to hear from people with personal experience of using the Independent Living Funds. We arranged a programme of consultation

meetings which were held in: Newport; London; Belfast; Edinburgh; Leeds and Birmingham. In total this provided an opportunity for us to consult directly with more than 120 service users and family carers. The meetings were lively and were well received by participants. Written summaries of discussions were produced following each meeting, and these were subsequently woven together in a document identifying the cross-cutting themes that emerged across all six meetings. This paper was written primarily as a feedback document that was shared with all those who participated in the meetings. The document was well received and has been circulated more widely. It is included as Appendix 2 of this report.

The Independent Living Funds: origins and nature

- 1.9 The original Independent Living Fund was established in 1988 as a result of the reorganisation of the social security system which introduced Income Support in place of Supplementary Benefit. The new system was a simplified structure and did not replicate a system of domestic assistance allowances that had existed within Supplementary Benefit to support severely disabled people who lived at home rather than in residential accommodation. Some 300 people would be affected by this change and transitional arrangements were introduced to provide some protection. It was then decided that new arrangements would be required for the future. Discussions with the Disablement Income Group (DIG) led to the establishment of a discretionary charitable trust under the auspices of DIG to provide financial help towards the costs of care for severely disabled people on low incomes and to enable them to live independently in their own homes. This was the establishment of the Independent Living Fund (ILF), which was envisaged as a temporary arrangement with a lifespan of five years. This was because at the time it was introduced other policy changes were in train which were expected to address the needs of disabled people in a more coherent fashion, most notably the Griffiths review on community care,² and a national survey on disability by the OPCS.³
- 1.10 The report from Sir Roy Griffiths was followed by a White Paper on community care⁴ and subsequent legislation which foresaw responsibility for funding the care costs of severely disabled people passing to local authority social services departments. However, the ILF was proving highly popular and within the first year of operation (1989/90) applications were received at the rate of 900 per month, rising to 2000 per month by November 1992. Between April 1988 and March 1993, at its peak the ILF made payments to more than 23,000 disabled people at any one time. In the light of this popularity the Government made a commitment to maintain a fund to support this group of people rather than transferring all of the money (and responsibility) to social services. This led to the creation of two new funds, and since 1993 there have been two Independent Living Funds in operation:

- **the Independent Living (Extension) Fund** which maintains the commitment to existing clients prior to 1993 which closed to claims from new applicants on 31st March 1993; and
- **the Independent Living (1993) Fund** to consider new cases from 1st April 1993.

- 1.11 However, because major changes were being introduced in community care which placed primary responsibility for the care of all disabled people with local authorities, it was decided to build in some direct partnership between the 1993 Fund and local authorities. Specifically, applicants to the ILF had to be in receipt of social care services to the value of £200 a week from their social services department before assistance could be provided by the 1993 Fund (after Direct Payments were introduced the £200 threshold could be made up of services or cash). Local authorities themselves received additional money - the Independent Living Transfer - that was to be separately identified in ear-marked funding for three years before becoming included in the Revenue Support Grant. While the Extension Fund can (at current rates) make weekly payments to a maximum of £785, the 1993 Fund has a ceiling of £455 per week (reflecting the partnership with local authorities). The ILFs are managed by a Board of Trustees and operate under the terms of two Trust Deeds. From 2007 it is anticipated that the two ILFs will operate under a single new Trust Deed. There are other eligibility criteria for the 1993 Fund, which are summarised in Box 1.1 below.
- 1.12 There have been incremental changes in the rules for accessing the ILF since 1993 in respect of the capital limits, earnings disregard and maximum weekly amounts payable. It is striking, however, that the £200 minimum threshold of social care services/cash that a person must receive from social services has not changed since 1993. The maximum that the ILF can pay is also of particular interest. When the local authority weekly contribution is £200 the ILF may contribute up to a further £375 per week (i.e. a total package value of £575). With a package value of £625 the local authority must contribute £250, and above £625 contributions from the ILF and the local authority are made on a 'pound for pound' basis. However, for the first six months of support from the ILF, the total package of the ILF and local authority contribution cannot exceed £785 a week (although other contributions to funding – such as from Supporting People, private income, or through the NHS, may be additionally available), after which there are no maximum ceilings. In effect this means that people with the highest needs for support are precluded from applying to the ILF. As we will go on to explore in this report, this matter recurred as a central concern in the evidence.
- 1.13 The origins of the limits on ILF and social services contributions appear to be based on an estimate at the time that the 1993 Fund was introduced of the average cost of providing residential care. The belief about the cost-effectiveness of ILF and local authority support for people in the community was therefore linked to an understanding that this should not be greater than the cost of providing residential care. Again, this is a matter that we will return to in the course of our analysis.

Box 1.1
Eligibility Criteria for the 1993 Fund

Applicants to the Independent Living (1993) Fund must meet all the following criteria:

- Must be living in the UK.
- Be at least 16 years of age and under 66.
- Must receive the highest rate care component of Disability Living Allowance (DLA), or Attendance Allowance (AA) or Constant Attendance Allowance (CAA) in certain circumstances.
- Have savings and capital of less than £18,500.
- Must expect to live independently for at least the next 6 months.
- Must not be living in a home.
- Must receive at least £200 worth of funding/services each week from the local authority and assessed as needing additional care.
- Must be in receipt of Income Support (or Pension Credit Guarantee) or have met a weekly resources test.

ILFs Status and Governance

- 1.14 Since 14 September 2005 the ILFs have been designated an Executive Non Departmental Public Body (NDPB) by the Cabinet Office, and are subject to NDPB guidance and requirements, under the sponsorship of the Department for Work and Pensions (DWP), and within an accountability framework set by DWP Ministers. Both ILFs are administered and managed by a single Board of Trustees. Originally Trustees were not appointed under open competition and did not have time limited appointments (although these could be terminated by the Secretary of State). Since the establishment of the ILFs there have been wider developments affecting the nature of public appointments, particularly the 1995 report of the Nolan Committee on Standards in Public Life. All ILF Trustees now have fixed terms of appointment and since 2001 have been appointed through open competition. The new Trust Deed (expected to be operational in 2007) provides for a minimum of three and a maximum of nine Trustees; up to half of these may be users of the ILF, or relatives of a person receiving payments from the ILF. At the time of the review under the terms of the Trust Deeds there were seven Trustees on the Board, one of whom was also a beneficiary of the ILF. The ILFs are centrally administered from their Headquarters in Nottingham with 160 staff, and 84 self-employed ILF Assessors who undertake the assessments of applicants for the ILFs throughout the UK.

- 1.15 The broad mission of the ILFs is identified in their 2005/06 Business Plan⁵ as being to:
- provide high quality services for clients that ensure dignity and independence;
 - use public money as effectively as possible;
 - strengthen relationships with partners, notably local authorities;
 - provide assurance to Government that the Funds are contributing positively to independent living for disabled people;
 - demonstrate to all partners that the Funds are continually reviewing and improving their performance.
- 1.16 The ILFs operate as cash-limited Funds, and it is a duty of the Trustees to remain within their budget - £263.7 million in 2006/07. The Trust Deeds provide some discretion for Trustees, but any decisions made about new claims must also have regard to maintaining commitment to existing claimants, and remaining within budget. In the event that prioritising judgements have to be made, the ILFs are required to give priority to candidates who are young and in paid employment.

User profile information

- 1.17 Data published by the ILFs indicate that the combined number of people using the two ILFs at 30 September 2006 was 18,761. Almost 74% (13,863) of these were users of the 1993 Fund, while 4,898 (more than one quarter of the total) were still users of the Extension Fund. The numbers using the Extension Fund have fallen over time, as would be expected given that this is no longer open to new applicants, while the numbers using the 1993 Fund have continued to rise. Further detailed information on the profile of users of the ILFs is explored in Section 2.
- 1.18 The representativeness of the ILF population is an issue we will explore elsewhere in the report. It is not necessary to be in receipt of Income Support in order to qualify for an award, but the income of the applicant and that of any partner [since April 2002, excluding earned income] is considered in any assessment. As a matter of policy successful applicants are expected to contribute half of the care component of DLA and all of the Severe Disability Premium where applicable, towards the care costs. ILF awards are based on an assessment (by an ILF assessor) of actual personal assistance needs and the cost of meeting those needs. Most users receive between £100 and £400 per week - only a small percentage across both funds [12.3%] receives over £400. The largest awards are more common in the case of the Extension Fund where there is no mandatory top-up arrangement with local government.

The Quinquennial Review

- 1.19 Prior to the current independent review of the ILFs the only other formal scrutiny has been the Quinquennial Review of 2001, undertaken by the Department for Work and Pensions.⁶ In undertaking the review the DWP:
- wrote to outside organisations and individuals with an interest in the work of the ILFs to invite comments on all aspects of their work;
 - consulted the Trustees, management and staff of the ILFs, along with other Government departments with an interest in the work of the ILFs;
 - in addition the ILFs advised all their clients of the review and invited them to comment.
- 1.20 Responses were received from over 1600 ILF clients plus over sixty organisations and other individuals. At the time that the Quinquennial was undertaken there was considerable public anxiety about the prospect of the ILFs being closed down. Extensive press coverage of this issue led to many people writing to the review to protest, and at least two thirds of the responses were simply pleas for the ILFs to continue. The review noted that: “The vast majority were complimentary about the Funds aims and objectives, but there was a good deal of detailed comments about the operational policies.” Overall the Review concluded that the ILFs “form a vital part of overall Government provision for severely disabled people and that the function should continue.” However, a number of detailed suggestions for operational change were proposed dealing particularly with improved alignment with local authority charging regimes (paragraphs 101-2); incentives to work and encouraging greater independence (paragraph 68), and help in moving away from Income Support (paragraph 56).
- 1.21 The present review differs from that carried out as the Quinquennial in some important respects. Firstly, the independence from Government of the consultants undertaking the review is an important issue. Second, while it is only a few years since the Quinquennial Review was undertaken, this has been a period of considerable change and development in social care and the context for the current review is in many ways both much more complex, but also potentially more conducive to the pursuit of objectives around support for independent living. And finally, whilst the Quinquennial Review focused primarily on the mechanics of ILF functioning, we have been tasked with examining the ILFs in the wider, dynamic context. We will explore this context in greater detail below.
- 1.22 The central system of Quinquennial Reviews of agencies and NDPBs has been removed and replaced by two processes of end to end business process reviews and a ‘light touch’ process of reviews for NDPBs outside the scope of business process reviews. Full guidance has been issued on reviewing NDPBs.⁷ The Cabinet Office advises that reviews should be carried out with sufficient frequency to “give the department confidence that the NDPB is delivering high quality services efficiently.” As the ILFs will merge into a single Trust in 2007, the DWP believes this is an appropriate time for a review to be

undertaken. As noted at the outset of this paper, a two stage review model is proposed by the Cabinet Office that addresses two related issues:

- whether a specific NDPB continues to be the best way to deliver the services for which it is responsible;
- if so, how delivery of those services can be improved in the future.

1.23 In addressing these questions the review looks both at the wider strategic context within which the ILF is operating (now and in the future), but also considers the short to medium term future. Any recommendations need to have regard both to any major strategic changes, but also to the changes that may be required in an interim period in moving towards a new model. The distinction between the two stages identified by the Cabinet Office is not always apparent and the Guidance is clear that NDPB reviews need not be undertaken in two stages, stating that: “When seeking the views of customers, it may be more efficient to seek views on both the status of the organisation and how performance can be improved in the future at the same time.”

The guidance recommends that the main organisational options that should be considered for any NDPB are:

- abolition;
- agency status;
- NDPB status;
- contracting out;
- market testing;
- merger or rationalisation;
- privatisation.

1.24 The review should follow a two stage sequence at this point. First, deciding whether the function is required at all (ie: abolition) and secondly, if it is required, whether an NDPB model is the best way of meeting the relevant Departmental objectives. Reviewers are urged to examine a range of issues at both stages and these are summarised in Box 1.2 below. We will draw upon this strategic framework in presenting our analysis of the review findings.

1.25 However, as we will outline in Section 2, we will supplement this analysis with an additional operational framework founded on some key values and principles.

Box 1.2

Organisational options for the future of NDPBs

Organisational Options

- **The bigger picture:** to what extent does the NDPB contribute to the delivery of wider Departmental and Government objectives?
- **Links with others:** what links does, or should, the NDPB have with other organisations?
- **Past performance:** how has the NDPB performed against its aims, objectives, key targets and quality standards? How successful have its relationships been with its parent/sponsor department and ministers?
- **Customers' views:** what do the NDPBs customers and other interested parties think about its role and performance?
- **The future organisation:** how should the NDPBs services be delivered in the future?
- **Good practice:** what examples are there of good practice in how the NDPB has delivered its services?

Improving Performance

- **Performance targets:** how far do they reflect the NDPBs aims and objectives? Are they sufficiently comprehensive and stretching to drive improvement? How is performance validated?
- **Partnership working:** where could the NDPB develop joint working arrangements with other bodies to enhance the efficiency and effectiveness of service delivery?
- **New technology:** how can the NDPB make better use of new technology to improve the delivery of its services and functions?
- **Customers' views:** in what ways do the NDPBs customers think it can improve the way it delivers its services and functions?
- **Openness and accountability:** how far is the NDPB accountable to its customers and other stakeholders for the service it provides?
- **Freedoms and flexibilities:** how could the NDPB benefit from different freedoms and greater flexibilities?
- **Corporate governance and reporting:** how well are the NDPB departmental and ministerial roles and reporting arrangements defined, and how could this be improved?
- **Sustainable development:** to what extent does the delivery of the NDPBs services and functions meet the Government's objectives on sustainable development?

The Changing Policy Context

1.26 We take as our policy starting point the broad goals for public service reform as laid out in the 2006 Discussion Paper from the Prime Minister's Strategy Unit⁸ in which the vision is that public services will be:

- citizen centred and responsive;
- universal, accessible to all and, in the case of core public services, free at the point of use;
- efficient and effective, offering value for money for the tax payer;
- equitable, helping to reduce social exclusion and improve the life chances of the disadvantaged;
- excellent (high quality)
- empowering and involve citizens.

We find this to be a compelling vision and one that is highly relevant to policy in the sphere of independent living for disabled people.

1.27 As noted above, there has been considerable policy turbulence in areas which have major implications for the ILFs. Of particular importance are proposed reforms in social care, together with developments which indicate a seismic change in the Government's understanding of disability and a commitment to overcoming the associated disadvantage and inequalities. These developments are consistent with (and informed by) changes in 'ideologies of disability' which have occurred over the past twenty or thirty years. This report is not the place to present a review of the academic literature on the debate between the medical and social models of disability, and full accounts can readily be found elsewhere.^{9 10 11 12 13 14} It is evident that understandings of impairment, disability and the complex process of disablement have been radically changed, and traditional individualistic medical explanations have been challenged by a socio-political conceptualisation. Much of this challenge has been expressed in terms of notions of citizenship, participation and empowerment. As we will explore below, these conceptualisations are central to the emergence of the 'cash for care' programmes.

Improving the Life Chances of Disabled People

1.28 The most significant policy response to the changing ideological climate has arguably been evident in the report 'Improving the Life Chances of Disabled People' published in 2005 by the Prime Minister's Strategy Unit in conjunction with the Office of the Deputy Prime Minister (ODPM) and the Departments of Work and Pensions, Health, and Education and Skills¹⁵. The most striking feature of the report is the explicit manner in which it espouses the social

model of disability. This was evident from the outset in the definition of disability that was presented:

“disadvantage experienced by an individual resulting from barriers to independent living or educational, employment or other opportunities that impact on people with impairments and/or ill health.” [p5]

- 1.29 Several types of barrier faced by disabled people were identified in the report – attitudinal, policy and physical, all of which were seen to lead to disempowerment. It went on to say:

“The cumulative effect of these barriers is to marginalise disabled people from the mainstream of society and the economy. Removal of these barriers is the key to empowering disabled people and giving them the opportunity to exercise their responsibilities as citizens – in the home, in the community, and in the workplace. It is time to end the culture of dependency and low expectations, and move towards a society in which we invest in disabled people, empowering and supporting them to participate and be included.” [p5]

- 1.30 The report set out an ambitious twenty year vision for improving the life chances of disabled people, namely:

“By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society.” [p8]

Practical measures identified in the report address four major dimensions – independent living, support for families of young disabled children, transition into adulthood, and employment.

- 1.31 Independent living is said to ‘sit at the heart’ of the strategy, and the Life Chances report adopted a broad conceptualisation that is in line with the ideological shift outlined above. Independent living, it is said, “is not just about being able to live in your own home,” rather it is about providing disabled people with choice, empowerment and independence. It is emphasised that this does not mean that disabled people are expected to do everything for themselves, but that they are expected to have the biggest say in what they do, how they live their lives, and how they take responsibility for their lives.
- 1.32 The Government accepted all of the recommendations made in the report, and in recognition of the cross-departmental nature of the issue the Office for Disability Issues (ODI) – reporting to the Minister for Disabled People – has been established to help coordinate disability policy across government. The ILFs were only briefly mentioned (as one of the funding streams for Individual Budgets) in the Life Chances report, but it is evident that the values and practice of all agencies involved with disabled people will need to be consistent with this new approach and vision.
- 1.33 The ODI will report annually to the Prime Minister, and the first such report was published in July 2006.¹⁶ The Minister for Disabled People (Anne McGuire) observed in the Foreword that the Strategy Unit report had “marked

a real change in the way Government thinks about the impact of its policies and services on the lives of disabled people.” Indeed, it is stated that for the first time, “we took as our starting point the belief that people are not disabled by their impairments but by the way in which society responds – or doesn’t respond – to their needs and aspirations.”¹⁷ The ODI report also acknowledged that the strategic vision of the Life Chances report would not be enough, and equality will only be delivered “through real and practical change” enabling disabled people to make real choices about how they live their lives.

- 1.34 In order to gain a more detailed understanding of what is meant by independent living and the means by which services and funding streams to actively support it can be developed and co-ordinated, the ODI report also announced the establishment of a 12 month review of independent living. The Life Chances report had recommended the establishment of a ‘Task Force for Independent Living’ consisting of ministers and officials from central and local government “working with organisations of disabled people to develop imaginative new solutions across the health/social care/employment/housing interfaces.” In place of the Task Force a panel of experts (including disabled people) has been established to review independent living. The terms of reference for the review are summarised in Box 1.3.
- 1.35 We established contact with the Independent Living Review at an early stage and had discussions both with the director of the review (Dr Jenny Morris), and the Chair of the expert panel (Dame Jane Campbell).

Box 1.3
The Review of Independent Living

The 6 aims of the review are to:

- Consider and develop the business case for investment in independent living for disabled people.
- Identify the support and advocacy services necessary to enable independent living for disabled people and to develop a business plan for delivery and funding of these services.
- Develop options for improved consideration of the needs of disabled people who need support services in the planning process for mainstream services, with a particular focus on transport, employment, housing and access to health care.
- Consider whether any changes to legislation are required to support independent living.
- Propose long term steering mechanisms for ensuring the momentum on independent living is maintained, and
- Make practical recommendations for early action to improve independent living choices for disabled people.

- 1.36 A further important part of the context to development of the concept of independent living is a Private Member's Bill (the Independent Living Bill) introduced in the House of Lords on 8th June 2006 by Lord Ashley of Stoke (with support from the Disability Rights Commission), and reintroduced on 27th November 2006. The central focus of the Bill is to deliver stronger rights and entitlements to independent living for disabled people based on the principles of freedom, control, choice and dignity. Part 1 of the Bill sets out some key principles which must underpin the delivery of independent living:
- Enabling freedom, choice, control and participation.
 - The right of disabled people to self-determination and support in expressing their requirements and managing their lives.
 - Positive action to address discrimination and disadvantage for older disabled people, those from black and minority ethnic groups etc.
 - Protection of dignity and respect for family life.
 - Safeguarding the health and well-being of carers and avoiding undue dependency.¹⁸
- 1.37 Part 2 of the Bill places a duty on local authorities and NHS bodies to cooperate with each other and with key partners to promote independent living and improve outcomes for disabled people. The Bill also seeks to ensure:
- The right to a comprehensive assessment of their needs, often conducted by the individual themselves with support where necessary – but whichever is the case they will have one assessment designed to address their personal requirements in a holistic way.
 - The right to be told what level of resources their LA and partners intend to provide to meet their requirements.
 - A choice of a cash payment [individual budget], a delegated budget [where they nominate an agent/third party to manage the money on their behalf], services arranged by statutory bodies, or a combination of cash and services.
 - The Bill also enables cash payments to be extended to health services that support independent living but does not require this.
 - Pooled funds to eliminate multiple assessments, delay and fragmentation.
 - LAs and NHS bodies would be required to build capacity and support the long-term sustainability of user-led organisations including CILs.
- 1.38 The Bill – if enacted – would do much to give legislative effect to the Life Chances report. In particular, it would increase the choices available to people over their living arrangements and would provide safeguards against

disabled people being forced into residential care against their wishes. However, the Bill does not have Government support because of the major concerns about the potentially open-ended budgetary commitments, the rapid timetable for implementation, and the implications of pooled budgets. At the time of the ILF review the Bill had been reintroduced as a new Private Member's Bill in the current parliamentary session as the Disabled Persons (Independent Living) Bill.

Reforming Social Care

- 1.39 The social model of disability has also been increasingly prominent in the reform of social care as reflected in the 2005 Green Paper, Independence, Wellbeing and Choice¹⁹ and the subsequent community services White Paper, Our Health, Our Care, Our Say.²⁰ The Green Paper, for example, stated that:

“We want to move to a system where adults are able to take greater control of their lives. We want to encourage a debate about risk management, and the right balance between protecting individuals and enabling them to manage their own risks. We want to provide better information and signposting to allow people to retain responsibility, and to put people at the centre of assessing their own needs and how those needs can best be met.” [p.10]

- 1.40 In similar vein, the White Paper identified the following vision:

“People in the 21st century expect services to be fast, high quality, responsive and fitted around their lives. All public services should put the person who uses them at their heart. This applies especially to health and social care because all care is personal.” [p13]

- 1.41 The vision is said to encompass three ‘simple themes’:

- putting people more in control of their own health and care: a fundamental aim is to make the actions and choices of people who use services the drivers of improvement;
- enabling and supporting health, independence and wellbeing: the outcomes that people want for themselves are maintaining their own health, a sense of personal wellbeing and leading an independent life;
- rapid and convenient access to high quality, cost-effective care: services should be in places, and at times, that fit in with the way people lead their lives; organisational boundaries should not be barriers.

- 1.42 It is also important to understand that this new agenda is not confined to traditional conceptions of health and social care, but also ties in with the wider wellbeing agenda. Independent living is inescapably dependent on effective working to secure economic and social regeneration, strong and safe communities, and social inclusion.

- 1.43 Reform of social care has also come under the increasing scrutiny of various independent inquiries. Most significantly, the challenges associated with an ageing population have been repeatedly analysed. The Wanless Review of Social care – published in 2006 – set out to find sustainable solutions.²¹ As the report noted, at the heart of the issues “should be a debate about what social care will do in the future. How will it help people? What outcomes should it aim to achieve? Who should it help?”
- 1.44 We recognise that these questions are ones which must be addressed not only in relation to the care of older people, but in respect of social care more broadly. As the Wanless review argued, fundamental questions need to be asked when estimating the future resource requirement of social care. The need for reform in the way social care is funded is increasingly accepted. The various options identified by the Wanless review²² and by others (notably the Royal Commission on Long Term Care), need to be publicly debated. They are beyond the scope of our review but we are clear that questions about the future of the ILF ultimately need to be located within this much wider context of policy change and funding reform. In this report we are taking the view that our task is to identify a sustainable and value-based vision for independent living. We recognise that this will have implications for funding, but it is for others to make decisions about resource availability and relative spending priorities.
- 1.45 This section of the paper has covered the changes in ideology and broad policy thrust in some detail because it is important to address the new context within which all agencies involved with disabled people will have to work. Values are important; they are the basis of attitudes and they are the determinant of behaviours. It is therefore crucial that disabled people have confidence that agencies and individuals supporting them are cognisant of, and in agreement with, a shared set of values based around concepts of independent living that reflects their preferred way of understanding their social roles and responsibilities. The various ‘cash for care’ programmes provide the policy domain within which similarities, differences, opportunities and tensions will be played out.

The Cash for Care Programmes

- 1.46 Robbins²³ notes that the impetus for ‘cash for care’ schemes has come from a complex blend of imperatives:
- a clear voice from the Independent Living and Exclusion movements demanding an end to social exclusion, stigma and second class citizenship;
 - a sense among governments that the traditional European welfare states can no longer cope with ever increasing demand – a hope that cash payments will both empower the recipient and save the state money;
 - a trend towards ‘personalised’ responses to need.

- 1.47 In general there is a compelling argument that cash payments facilitate people living in the ways that they choose, rather than being given services to match preconceived assumptions about what is needed and how individuals should live. Such payments are argued to provide greater flexibility and control over when, how and who provides the support that people need, and evaluations consistently report very high client satisfaction.^{24 25 26 27}
- 1.48 The pioneering and symbolic importance of the ILF in the development of cash for care models must be acknowledged. This was the first large scale opportunity for disabled people to use cash to meet their support needs rather than relying on services provided by local authorities or families. As Pearson²⁸ points out, it was the experience of people using the ILF that demonstrated providing cash for people to organise their own support offered more choice, control and flexibility than direct service provision – experiences that led directly to a continuation of the ILF following the 1993 changes. However, the policy arena in respect of cash for care programmes has become more complex since the 1980s; and while the ILFs led the way in the early days, increasingly it is other models (Direct Payments, In Control and the emergent Individual Budgets) in which innovative approaches and flexibilities are being tested and promoted.
- 1.49 We conclude this introductory section of the report by describing the other self-directed care programmes that currently exist or are in development, and in doing so we set the policy and practice context within which the ILFs are being reviewed. Leaving aside the position of the Family Fund (which awards ‘items’ rather than cash to families with children and young people aged 15 and under who have a severe disability or illness), three main programmes can be identified:
- Direct Payments
 - In Control
 - Individual Budget pilots

It is important to emphasise that the ILF is a partner in the Individual Budget pilots (as one of the income streams) and is working closely with the In Control Programme – it is not the case that the ILF is an alternative to these more recent developments. Nevertheless, unlike the earlier days, the ILF is now only one player amongst several in respect of ‘cash for care’.

Direct Payments

- 1.50 It is only in the last decade that the power to make cash payments to individuals was extended beyond the ILF to local authorities (LAs). The passing of the Community Care (Direct Payments) Act in 1996 meant that from April 1st 1997 LAs were given the permissive power to make cash payments, or a mix of services and cash, in lieu of local authority commissioned services to disabled people who were willing and able to take

responsibility for their own care arrangements. Initially direct payments (DPs) were available only to people aged between 18 and 65, but from February 2000 eligibility was extended to those aged over 65, and from April 2001 to carers, parents of disabled children, and 16 and 17 year olds.

- 1.51 Availability has been further extended to people with short-term needs (such as someone who needs help at home while recovering from an operation) and for services to help disabled parents. In April 2003 regulations came into force that changed the power to offer DPs to a duty to do so - requiring councils to offer direct payments to all people using community care services, thereby making it mandatory for LAs to offer DPs as an option. However, DPs are not available to people in residential care, neither are they available for the health part of a care package where someone has an identified health need that falls to the NHS. Since 2002-3, the take-up of DPs has featured in the indicators against which social services performance is rated by the Commission for Social Care Inspection (CSCI). The number of Direct Payments per 100,000 adults in the population has increased from 36 in 2002-03 to 57 per 100,000 in 2004-05. CSCI has commented that while the growth is encouraging, direct payments still form a small part of overall service provision. Moreover, there is significant variation around the country in the take-up of direct payments. CSCI found an adult service user would be "16 times more likely to receive a direct payment in Sunderland than in Bracknell. This variation cannot be explained by differences in the demographic profiles of Councils." ²⁹

In Control

- 1.52 In-Control [IC] is an English programme jointly developed by Mencap and the Valuing People Support Team as a way of enabling people with learning disabilities and their family carers to take a more positive role in defining and shaping the social care support they receive. It connects closely with DPs and the ILF but has the broader purpose of redesigning the delivery of all social care in order to help shift whole service systems towards 'self directed support'.³⁰ There were six pilots involved in the original IC project:

LOCAL AUTHORITY	SPECIAL FOCUS
Essex	Developing a community focused brokerage service
Gateshead	Helping people move from residential services
Redcar and Cleveland	Helping people move from traditional day services
South Gloucestershire	Helping people return from living outside their borough
West Sussex	Helping people with high support needs
Wigan	Helping individuals and families through transition

- 1.53 The defining features of IC are those of self-directed support underpinned by fair entitlements. Self-directed support is described as a 7-step process by which a disabled person can gain control over their support.³¹ The seven steps are:
- self assessment
 - plan support
 - agree the plan
 - manage individual budgets
 - organise support
 - live life
 - review and learn
- 1.54 It is argued that in the past the assessment process has not put disabled people 'in control'. Accordingly four stages necessary for developing a self-directed system of individual budgets are identified:
- determining how individual budgets will be set locally;
 - defining how levels of need will relate to individual budgets so that disabled people can find out for themselves how much they can expect to receive;
 - developing a clear assessment procedure for validating self-assessment;
 - training and reorganising local care managers to use the new procedure.
- 1.55 A report on the first phase of In Control (from 2003-2005) was published in the course of our review. The evaluation addressed six key domains of: self-determination; direction; money; housing; support and community life. Key findings from the evaluation are highlighted in Box 1.4.
- 1.56 IC differs in some radical respects from the ILFs and DPs, and these differences will become apparent in the course of the report. It is important to note, however, that IC has grown beyond the pilot stage and even away from its initial learning disability focus. The programme has now been extended to include 60 local authorities, and the IC model is seen as potentially relevant for anyone who receives social care support.

Individual Budgets

- 1.57 A Government commitment to 'Individual Budgets' (IBs) has been made in several policy documents, most notably from the Prime Minister's Strategy Unit,³² the Department for Work and Pensions³³ and the Department of

Health.^{34 35} The most recent formulation has been in the White Paper, Our Health, Our Care, Our Say which has several key messages:

- Unlike DPs, which cover only local authority social care budgets, IBs will bring together separate funds from a variety of agencies including local authority social services, community equipment, Access to Work, ILF, disabled facilities grants, and the Supporting People programme.
- Individuals who are eligible for these funds will have a single transparent sum allocated to them in their name and held on their behalf. They can choose to take this money either in the form of cash, as provision of services, or as a mixture of both cash and services, up to the value of their total budget.
- IBs will be piloted and evaluated. The first pilots got underway in three 'early implementer' sites (West Sussex, Oldham and Essex), and the remainder came on stream during summer 2006. These will run for between eighteen months and two years and, if successful, will form the spearhead of a national implementation programme that could begin in 2009/10.

1.58 Subsequent to the White Paper there has been exploration of the scope for including transport in some of the pilots, and for the expansion of the concept further to take on a wider range of income streams. A report will be submitted in the summer of 2007. In addition, although the IB pilot programme is currently restricted to adults, DfES and DH are looking at the potential for further pilots that include disabled children, and scoping work for this possibility is currently underway.

1.59 The PM's Strategy Unit described the overall aims of the IB approach as being to ensure that resources are allocated and services delivered in ways that:

- personalise responses to need;
- enable people to have choice and to be empowered over responses to need;
- and support disabled people to help themselves.

1.60 In recognition of the complex nature of the programme, the pilot project is being underpinned by cross-departmental working; DH is taking the lead and working with DWP, ODI and the Department for Communities and Local Government - DCLG (formerly ODPM). A joint Ministerial Steering Group oversees the piloting and reports to the Ministerial Group on Life Chances of Disabled People. The pilot sites are supported by the Care Services Improvement Partnership (CSIP) which has produced a Site Support Implementation Plan that includes a small budget of £220k per annum to be shared between the sites.³⁶ CSIP will provide one to one support for each authority alongside regionally based workshops, guidance and sharing of knowledge by means of a dedicated website.

Box 1.4

Evaluation of the First Phase of In-Control 2003-05

Self determination is about people having control over important decisions. In Control found that people could take more control over their lives even if they had profound disabilities.

- Before In Control less than half (42%) the people were satisfied with the control they had. After 12 months of using In Control this had increased to 97%.

Direction refers to people planning the changes they want to make in the future.

- Before In Control 61% of the people were satisfied with their plans; at the end when people had control 90% were satisfied.

Money – the system of In Control is transparent about how much money people can get to help with their support (the Resource Allocation System).

- People were more satisfied with their money when they had control (from 45% at the beginning to 90% at the end).

Housing – In Control found that disabled people want the same kind of housing as other people – ordinary tenancies, family living or home ownership.

- At the beginning of the pilots 6 out of 10 people were happy with their home situation. At the end 9 out of 10 people were happy.

Support – the support and services that people need to live their lives. Once people had control of their support money more chose to use Personal Assistants (almost three times more people at the end than at the beginning). People made less use of day centres and ‘shopped around’ for the support that suited them.

- About half (48%) of people were satisfied with their support at the beginning, and *everybody was satisfied at the end* (100%).

Community Life – self-directed support should mean that disabled people have a life in the community like anyone else. When people had more control over their support they also had more friends and social contacts.

- At the beginning of the In Control pilots just over half (65%) the people were satisfied with their community life; by the end this had risen to 100%.

- 1.61 Individual budgets constitute a radical extension of the previous cash for care programmes. A Department of Health briefing³⁷ states they are intended to:
- allocate resources transparently, giving individuals a clear cash or notional sum for them to use on their care or support package;
 - streamline the assessment process across agencies, meaning less time is spent giving information;
 - bring together a variety of streams of support and/or funding from more than one agency;
 - give individuals the ability to use the budget in a way that best suits their own particular requirements;
 - allow support from a broker or advocate, family or friends, as the individual desires;
 - be delivered within local authorities' existing resource envelope.
- 1.62 The defining feature of IBs as opposed to the ILFs and DPs is the potential range of income streams beyond social care that can be pooled into an individual cash budget. The potential streams and notional annual expenditures (England only) are shown below. The precise figures involved may be a matter of debate; the point of reproducing them here is to illustrate the relative contributions of the different funding streams.

INCOME STREAM	ANNUAL EXPENDITURE (£)
Social services expenditure on adult social care	15,000,000,000
Supporting People	1,680,000,000
Independent Living Fund	220,000,000
Disabled Facilities Grant	120,000,000
Integrated Community Equipment Service	52,000,000
Access to Work	60,000,000

Simon Duffy (2006), 'The implications of Individual Budgets', *Journal of Integrated Care*, Volume 14, Issue 2, April. Table 3.

- 1.63 The pilots do not all cover every one of the six income streams, or address the same issues or groups of people, although all will include social care services provided by the council. All but one of the sites (Norfolk) has indicated that

they intend to include ILF within their IB pilot. The 13 pilot sites are the local authorities of:

- Barnsley
- Bath and North East Somerset
- Coventry
- Essex
- Gateshead
- Kensington and Chelsea
- Leicester
- Lincolnshire
- Barking and Dagenham
- Manchester
- Norfolk
- Oldham
- West Sussex

1.64 Three research units are working collaboratively to evaluate these pilots (known as the IBSEN project – the Individual Budgets Evaluation Network) – the Personal Social Services Research Unit (LSE, University of Manchester and University of Kent), the Social Care Workforce Research Unit (King’s College, London) and the Social Policy Research Unit (University of York). The core aim of the evaluation is to identify whether Individual Budgets offer a better way of supporting disabled adults and older people than conventional methods of resource allocation and service delivery; and, if so, which models work best for which groups of users. This work can be expected to have significant implications for the ILFs.

The research will focus on five main themes:

- experiences and outcomes for users and carers;
- cost-effectiveness in comparison with standard approaches;
- implications for social care and other agencies, such as health, and for service providers;
- how services purchased by individual budgets are identified, managed and coordinated;

- workforce implications in terms of financial, management, legal and professional issues.
- 1.65 The evaluation will involve randomisation of clients to IBs in order to properly answer questions about whether Individual Budgets offer a better way of supporting disabled adults and older people than conventional methods of resource and service allocation, and which models work best.

Summary

- 1.66 This introductory section of the report has necessarily been quite lengthy in order to lay the ground for our subsequent analysis. The ILF is not well known and we have not wanted to assume familiarity with the way it is structured. Again, the changing ideological and policy context has been described at some length because the new value base constitutes the starting point for our own understanding and analysis. And finally it has been important to explain the nature of our own appointment and how we have undertaken the review. Our aim has been to produce an evidence-based report set within a clear framework of values, and section two begins the analysis of our review findings in accordance with this position.

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³¹ In Control (undated), *Individual Budgets: Guides to self-directed support*, Version 4.0.

³² Cabinet Office (2005), *Life Chances*

³³ Department for Work and Pensions (2005), *Opportunity Age*, London.

³⁴ Department of Health (2005), Op Cit.

³⁵ Department of Health (2006), Op Cit.

³⁶ Routledge M and Porter Z (2006), *Individual Budget Pilot Programme: Site Support Implementation Plan*, London: Care Services Improvement Partnership.

³⁷ Department of Health (2005), *Individual Budgets*, Gateway Reference 5993.

Section 2: Operational Framework

- 2.1 In the course of the review we received many positive comments about the ILF, particularly from service users and their family members. Many of the people who wrote to us emphasised the change that the ILF had made to their lives, and similar comments were made in the course of the six consultation events (see Appendix 1). Box 2.1 highlights a sample of the comments that were typical of many.

Box 2.1

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 love this service; it’s enabled my son to have more social activities he’s integrated well into the community. And it gives me, his main carer, a much welcomed respite.”

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

“The help and support the ILF have given me over the past 11 years has been invaluable in my socialisation both physically and emotionally in today’s modern society. For I am now able to go to certain venues like the theatre and the cinema and even go away for breaks with my PAs which, as my speech was badly affected in the RTA I was involved in, has been only beneficial and therapeutic in my progressive recovery.”

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

“..without ILF our lives would be terrible and very stressful..”

“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.”

“I feel I must tell you how the ILF has helped me to have a better lifestyle and more ‘me’ time.”

2.2 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 which enables them 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 need to unpack the valued features in much greater detail, and we do so by analysing the operational framework of the ILF. The operational framework of the ILF 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 have chosen to evaluate the operational framework of the ILF against the following six criteria:

- **Equity:** the extent to which people can get the help they need to fulfil their role as citizens; equity between all people needing help, so that some client groups are not favoured over others.
- **Transparency:** the extent to which people know how much money they are entitled to spend in order to make plans for their lives; and clarity over how those decisions are made and can be challenged.
- **Accessibility:** the extent to which the rules and systems are negotiable and proportionate, and the extent to which the system is publicised and applications encouraged.
- **Self-Determination:** the extent to which people have the authority, support or representation to make their own decisions.
- **Flexibility:** the extent to which people are free to spend their funds in ways that make most sense to them, with minimal interference.
- **Values and Outcomes:** the extent to which the system is geared towards what people value and achieve in terms of an improved quality of life and user-defined outcomes.

2.3 In the sections which follow we analyse each of these in turn and draw upon the evidence we have amassed to illuminate each dimension. It is important to emphasise at the outset that the values and principles we are following have been informed in particular by the views of service users, both from this review but also from a considerable body of research by ourselves and others over the years which has allowed a detailed picture to be constructed that identifies the features of social care services that matter most to their users.

Operational Framework: Equity

2.4 In analysing matters of equity the central issue at stake is the extent to which people with similar needs and requirements have equal access to support. We have taken this principle to apply across the whole spectrum of the disabled population. It is evident that the total number of people supported via the ILFs is very small compared with the potential client population. We distinguish

between two types of equity – that between different groups of user, and that between different geographical areas.

Equity Between Different Groups of Users

- 2.5 The User Profile Analysis produced by the ILF shows that at September 30 2006:
- 18,761 people were being supported: 73.9% via the 1993 Fund and 26.1% through the Extension Fund;
 - 51.2% of recipients were female and 48.8% were male;
 - 35.4% of recipients were aged 35 or less; 42% were aged between 36 and 55; and 22.5% were aged 56 and above;
 - 4.9% of recipients were from black and minority ethnic groupsⁱ, but data on ethnicity was unavailable in 37.8% of cases;
 - 38.4% of recipients live with a parent or parents; 28.7% live alone; and 14.9% live with a spouse or partner;
 - 62.5% receive income support and 11.3% receive pension credit;
 - 31.7% of users have a severe learning disability, 14.8% cerebral palsy and 13.4% have multiple sclerosis; no other category exceeds 7%, but 20.5% fall in the miscellaneous category of 'other'.
- 2.6 During our consultations, and in the submitted evidence, one of the most prominent issues raised has been the view that this spread of support is inequitable – that there is no logic in terms of fairness in the way that some groups access support and others do not. In particular we have received representations concerning the following categories:
- older people
 - former long-stay hospital residents
 - people with very high support needs
 - people with substantial support needs
 - treatment of partners and parenting.

ⁱ Throughout this report we use the term 'Black and Minority Ethnic' (BME). This is the preferred form of words used in most organisations and Government Departments, but we recognise that there are different views about terminology.

Older People

- 2.7 If someone is already receiving support from the ILF before they are aged 66 they can continue to receive it (so long as they satisfy all the other eligibility criteria), but they cannot apply to the ILF for the first time if they are 66 or older. Criticism of this restriction was a recurring theme in our consultations and evidence. The exclusion of initial applications from older people is not a restriction devoid of logic. First of all it is consistent with the logic of tying ILF into the criteria for accessing DLA, and in doing so reflects the origin of the ILF within the social security system (outlined in Section 1). More broadly it is consistent with what was often described to us as ‘the whole DWP mindset’ in which there are benefits for children, benefits for working age adults and benefits for older people, each with discrete boundaries. Secondly it is consistent with the ILF requirement that recipients should expect to live in the community for the next six months, since many older people will have an intrinsically unstable condition which makes such a prediction problematic. And finally, there is some basis in equity with the argument that those who are disabled from an early age tend to be more disadvantaged than those disabled after pension age.
- 2.8 On the other hand, there was a strong view repeatedly expressed that the exclusion of older people was merely a financial rationing device - the line taken in the 2001 Quinquennial Review¹, for example, was that the number of potential claimants aged over 65 would simply pose excessive budget implications for the ILFs. Estimates of the cost of extending ILF to all older people are uncertain but it would undoubtedly be much higher than could be afforded under current budget limits. If budgetary restrictions remain unchanged then there may well be a case grounded in the principle of equity for favouring younger disabled adults over older disabled adults. Evidence submitted from the Inverclyde Centre for Independent Living, for example, argued that:
- “While not wanting to appear ageist we feel it is important to ensure the limited funds available are utilised to their fullest by supporting more younger clients to remain in and be a full part of the community.”
- 2.9 In general, however, we received an overwhelming view that the continued exclusion of older people from ILF support is unduly inequitable, is inconsistent with the eligibility criteria for direct payments and, more broadly, is at odds with the thrust of government policy in other spheres such as employment and lifelong learning. Hampshire Centre for Independent Living has described the age limit to us as “blatant ageism and obvious discrimination.” Age Concern England similarly has referred to “a blatant form of age discrimination” and expressed the view that it is arguably in breach of the European Convention on Human Rights, whilst the Royal National Institute for the Blind argues that the restriction effectively cuts off applications from the vast majority of blind and partially sighted people, while others argued simply that such continued discrimination “has no place in society.”
- 2.10 Given the desirable trend towards the inclusion of older people in all facets of social and economic life, we can see no persuasive logic or equity in a

programme that implies independent living should cease upon the attainment of pensionable age. This is an outmoded assumption and, moreover, one that runs counter to the stated policy of continued support for independence in later years (as set out, for example, in *Our Health, Our Care, Our Say*²). We are therefore strongly of the view that the ILF and any future programme of which it is a part should be accessible to disabled people aged 65 and over on the same basis as for younger people. We understand that there is currently no reliable estimate of what this might cost, and we also appreciate that the sums required may not be immediately available. In written evidence to the review the ILF itself identified its wish to see changes that would enable it to widen its “breadth of engagement” with client groups, and specifically to see the upper age limit “raised progressively in line with government decisions in related policy areas on treatment of older people.” **We recommend that work begins immediately on an inter-departmental basis to estimate the cost of extending the ILF in its current form to older people and that a clear medium term timetable be laid down for implementing this extended access.**

Former Long-Stay Hospital Residents

- 2.11 The exclusion of long-stay and former long-stay hospital residents from ILF funding is likely to apply in practice only to people with a learning disability or people with mental health problems. We have not been in a position to study this issue in depth, but it would appear to have been a source of difficulty and confusion for several years, and was a recurrent issue identified in the course of the review. DWP and ILF seem to have been under the impression that former long-stay residents have continued to have access to funding under the old ‘dowry system’ (funded by the NHS) when in fact this source of earmarked funding ceased to exist several years ago. We were told that a compromise position had been reached several years ago whereby ILF could not be applied for as people were moving out of a long-stay hospital, but could be potentially accessed if people subsequently moved on to independent living arrangements. This compromise position does not seem to have been implemented, with ILF said to have stated in its training manual that no-one who had ever lived in a long-stay hospital was eligible for support.
- 2.12 It is understandable that the ILF should be wary about taking on additional commitments for which there is no identified funding stream, but political pressure and the threat of legal action appears latterly to have brought about some change in arrangements. The current position seems to be that the ILF will agree to the earlier ‘compromise’ solution by accepting applications from people on a ‘second stage’ move, but not from those moving directly from hospital or from associated ‘campus’ accommodation.ⁱⁱ Those who raised this issue in evidence to us expressed continuing confusion about the position of this group of people, with some arguing that the ILF does not seem to fully understand the issue.

ⁱⁱ Since the cut-off date for our evidence collection the ILF informed us that since October 2006 Trustees have agreed to take applications from some former long stay hospital patients.

- 2.13 We are not in a position to unravel the various positions that have been taken on this important matter, but what is clear is that – as in the case of older people – there is no reliable estimate of the cost to the ILF of taking applications from former long-stay hospital residents, albeit that in their written submission to the review the ILF cited a DWP estimate of £65 million per annum as the potential cost of extending ILF entitlement to people currently in campus accommodation “although specific subset groups could be targeted at much smaller cost.” It cannot be equitable to establish a stream of funding for independent living and deny it to some categories of user simply because their funding has historically come from the NHS rather than local government. **We recommend that work begin immediately on an inter-departmental basis to estimate the cost of extending the ILF to residents of long-stay hospitals and campus accommodation and to former residents of such accommodation now living in the community, and that a clear medium term timetable be laid down for implementing this extended access.**

People with Very High Support Needs

- 2.14 The rules of the ILF are such that currently there is an upper limit on how much money can be paid on a weekly basis for the first six month period of ILF support. The maximum weekly sum as from April 2006 is £785 in the Extension Fund (which is ILF money only), and £455 of ILF money in the 1993 Fund subject – for the first six months - to an overall limit of £785 from both the ILF and the Local Authority. A third party such as the NHS is able to put in any additional contribution over and above the maximum weekly sum as it deems appropriate. The rationale for this upper limit is obscure – we have been told variously that it was to avoid taking on very high cost terminal cases, and that it served as a yardstick for cost-effectiveness in that support beyond the upper limit could be provided more cheaply in residential settings. The existence of this upper limit serves to screen out the most expensive cases that would involve an increase in maximum weekly payments that could not be afforded within the current ILF budget.
- 2.15 Some support for the notion of an upper limit can be found. The Inverclyde Centre for Independent Living, for example, takes the view that it is a useful tool to encourage funding from other sources such as the NHS and Supporting People. In general, however, we have found dissatisfaction and even incredulity at the existence and impact of the upper limit. West Lothian Council told us that ‘the upper limit of combined LA and ILF funding is unnecessarily restrictive and is a disincentive to look at more imaginative and flexible care packages as alternatives to residential care’, and Newport City Council described the upper limit as the ‘principal shortcoming’ of the ILF, stating that:
- “This restriction prevents many people who are moving into supported living schemes as tenants from accessing ILF as the typical care package tends to be in excess of £1000 per week. It also prevents many young people with disabilities from receiving ILF support while they are in college placements as again the weekly care costs are well in excess of the ILF £785 threshold.”

2.16 Several witnesses went on to point out that the £785 maximum does not even equal the national minimum wage requirement for a 24 hour package of care.

2.17 As some other respondents pointed out to us, the upper limit on the ILF also fails to keep pace with other developments in health and social care. In particular, it is far more possible for someone with high level needs (particularly following a head or spinal injury) to live in the community than it was even a decade ago, and the issue of the maximum payment is thus encountered as a barrier more often than it might have been in the past, as this comment emphasises:

“It is relatively common now for a younger newly disabled person following complex medical treatment and discharge into the community to warrant an extremely high level of support in the community above the initial maximum funding level.”

2.18 In describing change to the upper limit as ‘the most overdue and urgent reform’, Edinburgh City Council argues that whilst it is understandable that the ILF wishes to set a limit on its own contribution, there is no clear rationale for also capping the local authority contribution at an arbitrary level unrelated to any assessment of need. Several problematic consequences of this restriction were related to us, including:

- impact on those needing two person support: no consideration is given to users who need two people for particular circumstances such as bathing and hoisting;
- insensitivity to variable local costs: the uniform ceiling is applied across the country even though care costs vary significantly from authority to authority;
- impact on those with initial high needs and costs: some individuals such as those moving on from more dependent arrangements need an initial higher level of support that will reduce as they become more confident in new settings.

2.19 What all of this adds up to is that the people whom ILF might have been most expected to help – people needing very high levels of support – are effectively excluded from even applying. Some respondents such as Medway Council suggested to us that this currently excluded group should, in fact, be the highest priority for the ILF. Our view is that the current imposition of a combined limit of £785 per week from the ILF and Local Authority has created significant inequity of access to support and should no longer apply. Whilst we can understand the need for a ceiling on the ILF contribution as the scheme is currently structured, we see no need to arbitrarily limit the local authority contribution. Evidence from the ILF identified the wish “to raise and ideally remove the upper limit for the first six months on the size of package to which the ILF can contribute funding, whilst maintaining a maximum ILF contribution.” It was emphasised that this would enable ILF to extend support to more people on HRDLA support “who might otherwise remain indefinitely in expensive and inappropriate residential care.”

- 2.20 **We recommend that work begin immediately on an inter-departmental basis to estimate the cost of removing the joint ceiling cap and that a clear medium term timetable be laid down for implementing full access to those with very high support needs who are currently precluded from making an ILF application.**

People with Substantial Support Needs

- 2.21 The current rules and regulations not only exclude many of those with the highest support needs, but also many people with lesser but nevertheless substantial needs. Applications to the 1993 ILF Fund are only open to people who receive the highest rate care component of Disability Living Allowance [DLA], while some existing users of the Extension Fund are in receipt of Middle Rate Disability Living Allowance [MRDLA]. For users of the 1993 Fund this can give rise to two types of inequity. First there is that range of people who currently receive only the middle rate DLA (perhaps because they sleep reasonably well at night) despite having very substantial daily support needs. We received representations in respect of a number of such categories of disability:

- people with a learning disability: Torbay Care Trust point out that many people with learning disabilities have significant day time needs but their night time needs may be deemed too low to meet the criteria for high rate care;
- blind and partially sighted people: the RNIB states that blind and partially sighted people usually only get the low or medium rate of DLA but that this is based upon a misperception of the support they need.
- asperger syndrome/high functioning autism: the National Autistic Society argues that it is difficult for people with these conditions to access support because they fall between the gap of learning disability and mental health and their needs are insufficiently understood and acknowledged;
- people with mental health needs: it was suggested to us that the higher rate DLA tends to be overly concerned with activities of daily living and insufficiently sensitive to mental health needs.

- 2.22 A second type of inequity arises where people have fluctuating conditions that might result in the loss, either temporarily or permanently, of higher level DLA. Wirral Adult Social Services told us that this was especially the case with mental health, stating that:

“A high proportion of people with mental health needs who use our services receive medium DLA but do not want to go through the process of applying for the higher rate because of fluctuating needs. They would rather not ‘rock the boat’ in case at some future date the money is reduced again to medium level because stable finances are more important to them.”

- 2.23 Others also highlighted the problem of ILF funding stopping immediately if DLA is reduced or lost on review, and the traumatic impact of losing two sources of income at the same time. It is in such circumstances that many witnesses called for the receipt of either the middle or higher rate of DLA to be sufficient ground for eligibility to apply for ILF funding. It is evident that many people in receipt of only the middle rates of DLA nevertheless have very substantial daytime needs for support in respect of their living arrangements, and it is not equitable to refuse even a consideration of their circumstances simply because of the historic linking of ILF to the social security system. **We accordingly recommend that receipt of the middle rate care component of DLA should not preclude recipients from submitting an application for ILF funding.** Other criteria will, of course, continue to apply, but these too may change in the light of other recommendations in this report.

Partners and Parenting

- 2.24 We have placed the treatment of partners and parenting together because they reveal some unusually dated assumptions about the nature of family life for disabled people. In the case of treatment of partners the ILF currently takes into account the income and capital of any partner in determining access to an award – capital has to be less than £18,500. This can introduce some perverse incentives into a personal relationship. At our Edinburgh consultation, for example, a young disabled woman remarked that “It’s like saying that if you marry me it will cost you a fortune.” A trenchant criticism from the perspective of a non-disabled partner was given to us in written evidence and is worth quoting at some length:

“As somebody who has recently married a disabled person I was interested to discover that I am expected under the ILF rules to pay for his support workers or else to reduce my savings to such a low threshold as is required for him to claim from the Independent Living Fund. My husband is disabled following a stroke and lives at home with support as he has now a cognitive impairment. I am 16 years younger than he is and I find I may have done him a disservice by marrying him as he cannot now receive ILF owing to my savings. I am expected by the Government to provide for my own retirement and yet if my husband claims ILF then I will not be able to save to do so and actually must spend my savings. It appears therefore that the ILF rules do not envisage a disabled person having a right to marry without an immediate enquiry into the monetary position of the spouse. I also fail to understand why by marrying a disabled person under ILF rules I become responsible for his care. Hardly a good start to married life! It appears therefore that I am supposed to live at benefit level.”

- 2.25 Comparable difficulties apply in the case of disabled people who are parents (particularly for those who are single parents). The current position of the ILF is that in determining eligibility for an award it is assumed that disabled parenting is not part of personal care. An ILF user wrote to us highlighting the issue succinctly:

“At the moment if you are a disabled single person you do not receive any help for providing care for your children in the home or getting them to school etc. Single disabled mums don’t want someone to do this for them, they just want help to help them complete these tasks.”

- 2.26 This means not only that the ILF will not meet any of the costs of parenting but also that in calculating the £200 local authority contribution, no account will be taken of LA expenditure on parenting support – a ‘double whammy’ for disabled parents. Such a stance is contrary to guidance from the Department of Health on how local authorities should interpret the parenting role in undertaking assessment for adult social care, and again will have the effect of introducing perverse incentives into normal family life.
- 2.27 It seems to us that the assumptions that apparently underpin the stance of both the DWP and ILF on the treatment of partners and parenting both stem from an earlier era and are now grossly inconsistent with modern ideologies of disability. The assumption that disabled people will not become parents is quite wrong and the refusal to either support them or even recognise the contribution of local authority support is totally unacceptable. Much the same could be said of the way in which the income and capital of a partner is taken into account in determining any ILF award. The experience of our witness quoted above is apposite:

“Staff at ILF have been intrigued when I have spoken to them about it, saying that the rules do not contemplate that a disabled person might marry a person with some money.”

- 2.28 In written evidence to the review the ILF identified a number of ways in which it wished to see improvements in support for independent living. This included broadening the concept of qualifying support and services “to at least encompass parenting tasks.” Some of the changes sought by the ILF would require changes of policy or increased funding from DWP, while others might have been accomplished by the ILF exercising its discretion (such as where changes affect a relatively small group of people as is the case with parenting support).
- 2.29 **We recommend that ILF funding be available to support disabled people in their parenting role and that any local authority support should be considered as eligible expenditure in respect of the local authority contribution. We further recommend that the current requirement to take a partner’s benefits and capital into account be removed.**

Other Groups

Black and Minority Ethnic Users

- 2.30 The take-up of ‘traditional’ care services by black and minority ethnic (BME) users tends to be low, not least because the services offered have often not provided care and support in appropriate forms and environments. The advent

of 'cash for care' programmes potentially offers support that is more customised to their needs and expectations. As already noted, 4.9% of ILF recipients are from black and minority ethnic groups, but data on ethnicity is unavailable in 37.8% of cases. It is not clear to us why the percentage of ethnic minority users is so low, nor why the ILF is unable to provide ethnicity data for such a high proportion of its cases. Several witnesses such as the London Borough of Brent and the Spinal Injuries Association questioned the accessibility of ILF for black and ethnic minority users and we share these concerns. **We recommend that the ILF reviews its current approach to working with black and ethnic minority users as part of its Disability Equality Strategy and addresses the apparent under-representation of black and ethnic minority users.**

Education and Learning

- 2.31 Kent County Council made strong representation to us in respect of disabled students. Receipt of a Disabled Student's Grant does not, of itself, exclude someone from receiving help from the ILFs, but any element of funding towards the cost of care would be deducted from an ILF award. Although tuition fees and other grants are totally disregarded, the ILF has a strange position on student loans. Where an ILF applicant is eligible for a student loan, the ILFs take that amount into consideration as income available towards the cost of care regardless of whether the applicant actually takes out the loan. We cannot understand why the ILFs take this stance and it seems unfair to add unwanted student debt to the difficulties already facing disabled students, especially when the student loan is not specifically intended to pay for personal care. We believe there should be no such disincentive to gaining an education, and indeed those prospective students should receive positive support. **We recommend that both the Disabled Student's Grant and any student loan be disregarded in calculating an ILF award.**
- 2.32 We were also told about the problems faced by disabled parents who wanted to make arrangements for their children's further or higher education:
- "If you are a disabled person with children no account is taken for example of university tuition fees, so you might have a level of capital which you have specifically put aside to pay for your children's education (...) and the point is that should be taken into account."
- 2.33 Failing to take account of savings to pay for children's education arguably reflects beliefs from an earlier era when it was assumed (often wrongly) that disabled people would not have the same range of roles and responsibilities as other citizens and would not generally be partners or parents. We find such assumptions outmoded and inappropriate. **We recommend that the Conditions of Grant Agreement for the ILF should be renegotiated in order to take account of the costs which disabled parents face if their children are in further or higher education, and that assessment of capital should make adequate disregard of savings for this purpose.**

End of Life Users

- 2.34 As already noted one of the eligibility requirements for accessing ILF is that recipients should expect to live in the community for the next six months. This rule, possibly inadvertently, can have the effect of excluding people with terminal illness if their care package is not likely to remain stable for the next six months. We do not believe access to ILF support should cease because someone has less than six months to live. Most people express a preference for dying at home, but the reality is that this is achieved by only around a fifth of us, whereas almost 60% of people die in hospital and a further 20% spend their final days in nursing or residential homes.³ Support for people to remain independent and living in their own homes should not be contingent on their expected lifespan. Even if people are able to survive for only a short period with the extra support that the ILF would facilitate, we believe this would add enormously to their quality of life while receiving palliative care and might allow more people to achieve the 'good death' that they would prefer. **We recommend that people with a terminal illness that may last less than six months should be able to apply for ILF support.**

Equity Between Different Geographical Areas

- 2.35 We distinguished earlier between two types of equity – that between different groups of user, and that between different geographical areas. In the case of the latter type of equity the ILF has significant strengths but also some weaknesses in that it is a portable UK-wide benefit, but it is also characterised by wide variations in local take-up rates. We deal with each of these in turn.

ILF as a UK-Wide Agency

- 2.36 Perhaps the most distinguishing feature of the ILFs as compared with other programmes is the nationally determined nature of their arrangements - all of the other cash for care programmes are locally based and determined, albeit operating within some national guidelines. The ILF itself is in no doubt that this is a crucial advantage in the consideration of any future scenario, with other arrangements not seen as able to secure the requisite degree of consistency across every local authority in all parts of the UK. As the ILF Strategic Plan 2006-9 puts it:
- “The ILF does offer a degree of national consistency with expertise in needs assessment and review [and] a low cost administration base...we have a UK wide capability for consistency that is not constrained to local issues.” [para 3.1]⁴
- 2.37 In evidence to this review, the ILF repeated this point with force, comparing the stability of ILF funding with the instability of local authority sources:
- “The ILF approach guarantees that £270m of taxpayers' money is kept separate from local politics and pressures and is set aside by DWP at national

UK level and dedicated to the needs of severely disabled people – whilst at the same time levering in further monies from local Authorities across the UK. The current moves from a number of local authorities to limit support to “critical” and ban the use of direct payments for leisure demonstrate how vital this ringfencing is.”⁵

- 2.38 In our consultation exercises we were left in no doubt that service users much prefer the protected nature of the ILF budget to the vagaries of local authority systems, but there was a view expressed that the ILF tends to be ‘Anglo-centric’ in nature. Glasgow City Council told us that there is a bias towards English legislation in the workings of the ILF, for example the focus in charging policies on Fair Access to Care (FACS) rather than the system of free personal care in Scotland. This was described as “a source of confusion for customers and practitioners alike and requires urgent attention.” The ILF is proposing to introduce an additional geographical dimension to its organisation structure by creating regionally based staff who would be able to draw together and link networks of users, providers, local authorities and ILF assessors. These are sensible measures that should help to strengthen links between the ILF and the different parts of the UK, though it may be commented that it has taken rather a long time for such a basic idea to come to the drawing board. We have been impressed with the strength of feeling around the nationally determined nature of ILF and the portability of support when users move to different parts of the country, and this will form an important feature of our proposals for the future organisation of the ILF.

Variation in Take-Up of ILF

- 2.39 The variation in take-up levels of local authority direct payments has been well documented. An ESRC funded study into the implementation of direct payments⁶ concluded that:
- “Amongst the small number of disabled people who are receiving direct payments there is evidence of inequality with regard to their use by nature of impairment, local authority and part of the UK. This indicates that the potential benefits of direct payments are being unequally distributed, and these inequalities might intensify if direct payments are more widely used in the future.” [p83]
- 2.40 The nationally based nature of the ILFs might be expected to result in a fairly even geographical coverage of support, but in fact there are considerable variations. The Quinquennial Review expressed concern about the variable proportions of local authority social services users also making use of the ILF, with Fund clients as a proportion of total population in each LA varying between 1.5 per 100,000 population and 80.0 per 100,000. The Review concluded, however, that the ILFs were “making all reasonable efforts to acquaint individual LAs and their staff of the Funds” [para 53] and deemed it inappropriate for the ILF to develop regional or national take-up campaigns.

2.41 More recent figures published by the ILF suggest that the problem persists despite the efforts being put into local authority liaison. In England, for example, 63 local authorities have a take-up of fewer than two ILF users per 10,000 population, and 25 have a rate in excess of 4 users per 10,000 population. The variations across local authorities in England are repeated in the wider context of the UK, with England averaging 2.5 ILF users per 10,000 population as compared with 5.9 in Wales, 5.5 in Northern Ireland and 6.1 in Scotland. The position in Scotland is especially complex, with the Scottish Parliament having a greater degree of devolution in respect of health and social care policies. Some of the relevant policy areas and associated budgets are devolved and others are reserved – community care, education and health are devolved, Access to Work is reserved to Westminster because it concerns employment, and the ILF operates in standardised fashion throughout the UK.

2.42 We observed in our summary of feedback from the user consultation events ⁷ that:

”Before anyone can apply to the ILF, they have to know that it exists. A recurrent theme in all of the meetings was that the ILF is one of the ‘best kept secrets’ and that getting to know about it often depends on pure chance, or on being told about it by other service users. Local authorities, and different social workers, vary in their knowledge of the ILF and in the extent to which they actively encourage people to apply for it. There is no automatic process for ensuring that people who could be eligible are told about the ILF or helped to apply for it. Potentially there are many more people who could benefit from the ILF who have no knowledge of this.” (p4)

2.43 Our witnesses and evidence confirmed that individual social workers vary greatly in their awareness and understanding of the ILF. On numerous occasions people referred to the ‘lottery’ that operates in terms of whether or not people are aware of the ILF and encouraged to apply for it. Many local authorities have now appointed ILF Contact Officers and where they work in conjunction with ILF Coordinators there tends to be a higher level of successful application. We remain concerned and confused, however, at the recommendation in the 2001 Quinquennial Review that the ILF should not promote its availability and “that any national or regional take-up campaigns would be inappropriate” (paragraph 53), and this has contributed to the widely reported description of the ILF as ‘secret money’. The explanation for this can only lie in a wish to use lack of knowledge as a covert rationing device, and we do not believe this is a reasonable way to run a publicly funded service for people with high support needs. **We recommend that the constraints on the ILF stimulating demand and promoting take-up be removed, and that the ILF subsequently introduces all necessary measures to increase consistency of take-up in all local authorities across all four nations of the UK. Moreover, DWP should ensure that people receiving higher rate DLA are automatically given information in appropriate formats about applying to the ILF, and if our earlier recommendation is accepted this would also apply to people in receipt of middle rate DLA.**

Summary

- 2.44 The first principle we have looked at in respect of the operational framework of the ILF has been that of equity. We have noted the importance of the national portability of the ILF as a precursor of geographical equity, but also that there remains wide geographical variation in take-up rates such that ILF is widely known as 'secret money'. We have also noted that a wide range of people with very high support needs is currently excluded from routine access to ILF support, notably older people, people leaving long-stay hospitals, people with very high support needs, people with substantial support needs, some disabled people with partners, disabled people who are parents, black and minority ethnic users, people in learning and employment, and end of life users. This constitutes a formidable list and leads us to conclude that under current circumstances the ILF is characterised by an unacceptably high level of inequity that must be addressed as a matter of the utmost urgency. The importance of tackling many of these issues has been recognised by the ILF who have identified the need for changes in legal restrictions, DWP expectations and funding availability in order to facilitate a broadening and deepening of the ILF role.

References: Section 2

¹ Department of Work and Pensions [2001], *Independent Living Funds: Quinquennial Review 2001*. London.

² Department of Health (2006), *Our Health, Our Care, Our Say: A new direction for community services*, Cm 6737, London: The Stationery Office.

³ House of Commons Health Committee (2004), *Palliative Care*, Fourth report of session 2003-04, HC 454-1.

⁴ Independent Living Funds [2006], *Strategic Plan 2006-2009*. Nottingham.

⁵ Submission From the ILF to the Review Team (2006), ILF: Nottingham.

⁶Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestly, M. and Mercer, G. [2005], The Development of Direct Payments in the UK: Implications for Social Justice. *Social Policy and Society*, 4:1, pp75-85.

⁷ Henwood, M. and Hudson, B. (2006), *Talking to people who use the ILF: Feedback from 6 consultation events organised as part of an independent review of the Independent Living Funds*. (Included as Appendix 2 of this report)

Section 3: Operational Framework: Transparency

- 3.1 'Transparency' refers to the extent to which people know how much money they are entitled to spend in order to make plans for their lives; and whether there is clarity over how those decisions are made and they are open to challenge. In this section we explore a number of dimensions of transparency. It became apparent in the course of the review that people's experience of the ILF is often far from transparent: they do not know how their money has been calculated or how it should be; they have little knowledge of how the ILF operates as an organisation and who makes the decisions; and they are uncertain about whether and how they can challenge those decisions.

Discretion versus entitlement

- 3.2 The issue of whether payments to disabled people should be an entitlement or a matter of discretion goes to the heart of the debate about the role of the ILF. In Section 1 we outlined some of the historical antecedents to the establishment of the ILF; however it is necessary to explore something more of the detail of the debate that surrounded its location under the organisational auspices of DIG in order to understand how this has shaped the organisation and the way in which it operates to this day. At the time of the reform of the national social security system in 1987/88 a major campaign was mounted and the first national demonstration of disabled people took place under the banner of 'Rights not Charity'. There was enormous resistance among the disabled community to money being removed from the old Supplementary Benefits system and transferred to the responsibility of a charity. This was seen, fundamentally, as a transition from a rights-based, universal entitlement to a discretionary fund where eligibility would be more circumscribed. As one of our witnesses observed, "although we see the ILF do great things for individual people, politically and ideologically it just doesn't fit with our premise."
- 3.3 Accordingly there was considerable criticism and hostility surrounding the development of the ILF. While there was great support for the model of providing financial help for severely disabled people who didn't want to use outmoded or traditional services, or who had no choice other than residential provision, organising such payment via a discretionary charitable instrument was far less acceptable. Indeed, the idea that there should be a charity in charge of administering the fund was anathema to many disabled people. In many ways it was precisely the resistance to creating the ILF under the control of DIG that laid the foundations for the campaign which led eventually to the establishment of Direct Payments. ILF was seen as an organisation for disabled people, but not of disabled people. The model of the ILF was perceived by many in the disability community as an inherently flawed and highly paternalistic approach which failed to engage with disabled people, not least because until recently beneficiaries of the ILF have not been Trustees of

the fund.ⁱ The central tension in the rights Vs charity debate is summed up by this stark observation by one of our witnesses:

“So there has always been this view that the ILF should have been a universal benefit, and somehow down the line it got sort of sent off to these sort of charitable saints, which of course disabled people do not want because of the discretionary element.”

- 3.4 While many of the characteristics of the ILF were viewed with suspicion by the more political wing of the independent living movement, there was nonetheless support for the organisation being located under the responsibilities of the Department of Work and Pensions (DWP). It was argued by many of our witnesses that there is a logic to this location and the involvement of DWP creates opportunities for a rights-based entitlement to develop. In contrast the Department of Health was thought by many to offer a more traditional and ‘welfare’ type of model of support which would be far more unpopular. We examine these issues more closely in Section 11.
- 3.5 A system that relies on discretion rather than rights arguably has some inherent flaws and weaknesses. In particular:
- There are risks of inconsistent and arbitrary decision making.
 - There is a consequential difficulty of ensuring accountability for decisions made.
 - Challenging decisions is problematic since it is uncertain on what basis these have been determined.
 - There is uncertainty for users who do not know the basis for their access to support and hence live with the possibility that they will be deemed ineligible at some point in the future.
 - Finally – but perhaps most significantly – a system based on discretion tends to be seen (and experienced) as condescending and paternalistic.

All of these features arise from an underlying weakness which is the absence of transparency about how support is determined.

Transparency

- 3.6 The way in which the ILF operates is that following an application by a prospective user, a visit is made by an ILF Assessor. The visit is intended to

ⁱ The 1993 Fund did not allow beneficiary Trustees and the Extension Fund only permitted this through a scheme introduced by the Charity Commission in 2004. This is no longer the case and the new Trust Deed allows for up to half of the Trustees to be (or be related to) beneficiaries of the Fund. At the time of the review this was actually the case with only one Trustee, but in addition one further Trustee was a person with disabilities, although not an ILF beneficiary.

allow the ILF to find out more about the person's needs and to provide the information necessary for calculating the amount of money to be provided. The report made by the assessor to the ILF identifies how much support someone needs on top of the help that they receive from social services, and what this will cost. A calculation is made of how much the person should contribute themselves from their 'available income', and if successful an offer is subsequently made by ILF of the amount of financial support that can be provided.

- 3.7 This is a complex arrangement. Information issued by the ILF (and available via their website) illustrates just how complex it is, and even people who are experts in social care and the benefits system would find it far from straightforward to understand the process of how the value of support from ILF is determined. In addition to the issues around the assessment of income and capital there are further layers of complexity in understanding how support needs are established, and what account is taken of care provided not just via the local authority social services department, but also that provided 'informally' by family members – as this remark makes clear:

“Big gap in the plan – he cannot cope with the paperwork involved or organise the team or train them. We use a quarter of the care hours on that which means we as parents have to cover that – there isn't enough funding for admin or to give us a break. He needs 24 hour cover and we only have 10 hours per day.”

- 3.8 Many of the ILF users we spoke to, or who submitted evidence to us, commented on the complexity both of the ILF's approach, and of the published documentation and information. As this person remarked in evidence, “the small print associated with an award from ILF is a minefield.”
- 3.9 The financial assessment that takes place in parallel to the assessment of need means that people cannot easily predict the level of the ILF offer that they might receive. The level of the offer will depend not simply on their needs for support but also on the money they have available.
- 3.10 While the ILF is – as we have described previously – a national and UK-wide system, it is nonetheless evident that this does not mean that all ILF users have the same experience or expectations. Evidence submitted to us from Middlesborough Council, for example, stated that:

“This inconsistency is particularly apparent when applications are made from a shared care property. Despite identical information being submitted for a number of service users, the length of time for processing can vary from two weeks to seven months.”

- 3.11 How smooth or otherwise is someone's experience of applying to the ILF depends crucially on a number of variables that have nothing to do with their needs. There are no regulatory time frames for processing claims, and delays prior to making an offer can be lengthy. No guidance seems to be available as to the length of time ILF will take to complete this process, and service users have no influence or control over the matter.

- 3.12 In the course of the consultation meetings undertaken as part of the review it was evident that there were significant concerns and frustrations about the operation of the ILF and different experiences and understandings of how it functions in practice. The slowness of the initial application process was repeatedly remarked upon by service users and their family members. There are often considerable delays between someone contacting the ILF, having an assessment and receiving any payment. The following quotes from evidence make the point:

“..it took from the date of application 7 months to get a decision (...) many telephone calls, emails and letters later we finally were paid the maximum award, even at that stage there was a miscalculation. My pleas of hardship whilst waiting for a decision as my husband was undergoing surgery and was seriously ill and then unable to work for months were unheeded; I simply could not get a response of any kind for over 6 months.”

“It is an inefficient service and takes too long to process which has a massive impact on people’s lives.”

- 3.13 The ILF has set itself the standard of making decisions on new applications for assistance within 13 weeks. We regard this as excessively long; it is also apparent that many people have experienced delays considerably greater than this target.
- 3.14 Moreover, before anyone can even apply to the ILF, they have to know of its existence. A recurrent theme in all the consultation meetings (and indeed in other elements of our evidence gathering) was that the ILF is one of the ‘best kept secrets’ and that getting to know about it often depends on pure chance, or on being told about it by other service users. Local authorities, and different social workers within those authorities, vary in their knowledge of the ILF and in the extent to which they actively encourage people to apply for it.
- 3.15 **We recommend that the ILF reviews and simplifies its application processes and information for service users, and that it introduces meaningful performance indicators to drive improvements in its responsiveness both to new applicants and existing clients.**
- 3.16 Even once people succeed in accessing the ILF, they often have little or no idea about how it operates or how it arrives at its calculations. The ILF was described, for example, as being “shrouded in mystery”. It was evident even in the consultation meetings that ILF users were learning about the ILF simply from the stories that other users were sharing. Some people were clearly surprised to hear that others were getting payments, for example to pay for accountancy support. There seemed to be a general impression that if you ask ILF for specific financial support you might get it, but it would not be volunteered or made known to you and the onus would be on the individual to make the approach. As many service users remarked to us, this can be the value of being networked with other service users, such as through a local Centre for Independent Living, as this witness observed:

"Well it's how canny you are, quite frankly! But some disabled people will go by the book because they don't know any different. But most disabled people who are connected into the independent living movement - because we have a clear support network – know exactly how to use the fund for their own ends."

3.17 One service user, in written evidence to us, puts the problem succinctly:

"ILF policies and procedures still remain unclear and vague. Each user seems to be subject to a totally different experience and even differing rules, regulations and expectations. While a degree of flexibility works well when it is deemed favourable to the disabled user, it is distressing when it fails and there are no mechanisms to resolve matters satisfactorily."

3.18 There are clearly advantages for some people who are better connected to the independent living movement compared with those who are simply ILF users, as this witness also observed, "there is a big difference to being an ILF user and being someone who is engaged with the independent living movement." In part this is about passing on knowledge, particularly from people who have been involved in independent living for some time to others who are relative 'newcomers' or who might have become disabled suddenly as the result of a traumatic accident, but it is also about passing on advice to people to enable them to get maximum value out of the 'system' and to provide information that would not otherwise be available. Moreover, while those who are part of the independent living movement 'spread the word', it remains the case that most disabled people are not part of this community. We regard it as unacceptable that people's knowledge of how the ILF operates should be so heavily contingent on random factors such as how well-networked they are with other disabled people. We shall return to this matter in our examination of self-determination in Section 5.

3.19 A change in needs can also bring difficulties. One consequence of the long intervals between individual reviews (usually two years) can be that a deterioration or change in condition and needs goes undetected. Certainly the onus is on the individual ILF user to request a review of their situation if their needs have changed; but just as we were told that the ILF is slow to respond to initial applications, it is also clear that applications for review often take a considerable time to be handled. Evidence submitted to us highlighted problems of wrong payments being made over extended periods of time, and of major difficulties being encountered when requests were made to the ILF to resolve these. It was also clear that some people are reluctant to request a review or to challenge a decision because of the unpredictability of the action which ensues. The following comments from evidence to the review illustrate the difficulties:

"The worst aspect of this is that if there is any form of misunderstanding or doubt, the ILF stops all payments until they feel they are back in control."

"..the time taken to process any financial alterations or renewed offer letters to me have been increasingly longer."

- 3.20 The discretionary basis of the ILF decision-making can make it very difficult for ILF users to know when they could, or should, challenge the award they are receiving. Whether or not their situation is 'right' is hard to judge without any clear ideas of entitlement. It is often only by hearing about the experience of other people in a similar situation who have successfully challenged a decision that people realise they may have a legitimate claim.
- 3.21 Two particular examples of this lack of transparency were repeatedly given to us. First, the failure to uprate existing awards on an annual basis – ILF funding does not automatically rise with the cost of living, and users have to reapply each year to see if the ILF will fund the same level of support. The ILF stance is that 'anyone can come to us at any time' but this is burdensome and opaque for service users juggling with tight finances. It could be argued that automatic increases might discourage some users from raising genuine claims for a wider review of their needs. However, we do not find this a compelling reason for not making annual upratings. The second example is that of 'hidden information' about specific allowances, with some key elements such as national Insurance contributions, holiday pay, employers' liability insurance and payroll costs not included unless the applicant specifically requests them at the time of the assessment – a point when people will generally be unaware of their legal obligations and responsibilities as employers.

ILF Trustees and Staff

- 3.22 The transparency of the ILF as an organisation is about much more than how it determines the offers made to applicants. Crucially, it is also about issues of governance. We will explore these in greater depth when we turn to address the strategic framework later in the report, especially in Section 9. However, it is relevant to our current concerns to note that service users we met were typically unaware that the ILF is administered by a Board of Trustees, and on learning this fact immediately wanted to know who these people are and how they became Trustees. While views were split on whether all Trustees should themselves be disabled, it was generally believed that at minimum a majority of Trustees should have such personal experience.
- 3.23 The absence of a system for appeals on decisions to be made in person to the Trustees arguably adds to the invisibility and remoteness of the Board. In our summary of the consultation exercise feedback we reported that:
- “There was some criticism about the lack of awareness about appeals procedures and concerns that appeals to the ILF were not conducted in a transparent and open way.”
- 3.24 In written evidence to us, one service user said:
- “Most importantly the ILF is not good at handling complaints and criticisms in an adult manner. It is unable to handle a new generation of disabled people who butt the system and refuse to accept second best. Even at the most

senior level, it does not have the skills or understanding to handle complaints in a responsible and compassionate manner.”

3.25 Between April and September 2006 the ILF established a project to examine the processes for handling complaints and review of decisions. This was an explicit recognition that current procedures do not match best practice, and that the designation of ILF as an NDPB could bring intervention from the Ombudsman. At the time of writing (January 2007) no changes had yet been made as a result of this review project.

3.26 While the ILF has plans for improving the accessibility of Trustees through open meetings with service users, these have never previously taken place. More opportunities to have direct access to ILF staff and Trustees could improve the transparency of the organisation’s operation and help in shifting the culture to one that would be seen as more open and less defensive. There are also wider issues here about how the ILF relates to the users as a constituency, and we will return to this matter within the analysis of the strategic framework.

3.27 Many people reported favourable experiences of their contact with ILF Assessors (ILFAs). In our summary of messages from the consultation exercises we noted that:

“ILF assessors were seen as knowledgeable, friendly and helpful people who approached the assessment as a two-way discussion and who went out of their way to be helpful and to try to ensure that all needs were taken into account.”

3.28 We noted also in the same report that many people contrasted this with their experience of assessment from social services, with the latter often seen as simply trying to limit what support or funding people would be given. Nevertheless, ILFAs are limited in their ability to determine support inputs for applicants, having no authority to ‘sign off’ and agree an award. Moreover, we were repeatedly told of inconsistent decision-making by ILFAs. Worcestershire Social Services referred to “differences in interpreting and applying policy between ILF casework teams,” whilst Middlesborough Council told us that:

“We believe there is generally an inconsistent application of policy and a lack of communication internally within the ILF. Discretion is applied inconsistently, resulting in significant variations in approach to service users in broadly similar circumstances”

3.29 Leicester City Council made a similar point to us, stating that:

“The impression Council staff have is that there are very few fixed rules dictated by the ILF Trust Deed, and that outside these rules consistency is neither required nor seen as desirable. The effect is that it is extremely difficult, even for an expert, to predict what answer the ILF will give to any given question.”

- 3.30 Where such inconsistency exists, it can probably be traced back to the complexity and lack of transparency of ILF processes and procedures – a potentially Kafkaesque scenario in which neither the assessors nor the people being assessed have a clear understanding of the operating processes.
- 3.31 Much less positive impressions were formed of other ILF staff, particularly those encountered on the telephone. These quotes from the evidence are typical of many that were received:
- “The other problem is staff attitude. They do not seem to understand that their main purpose is to provide a service to disabled people. Such a service should be helpful and easy to understand, whereas my limited experience has been that they are ‘doing me a big favour’.”
- “I have had to contact the ILF (...) I have to say that this contact has in the main been less than satisfactory and has resulted in my having to spend many hours writing detailed letters to explain why the value of the award is incorrect.”
- “Many of them are quite rude and abrupt when I make an inquiry and they seem oblivious to the fact that I am obliged to place this call during peak hours.”
- 3.32 Cheshire County Council, in evidence to us, went so far as to identify ILF headquarters as “the main weakness of the ILF”, going on to describe:
- “...a restrictive and bureaucratic approach to the application of procedures. Administrative staff seem occasionally unable to recognise the effect their decisions have on disabled people’s lives, and will often simply suspend a person’s payments because of a minor error made by the disabled person in providing information to the ILF. On these occasions the ILFs administration staff are unbending and unsympathetic to a person’s situation.”
- 3.33 In the absence of transparency and clarity about how the ILF makes its decisions and offers, the preconditions exist for a culture to develop which is characterised by mutual suspicion and mistrust. From the perspective of ILF users this is experienced through a system which seems to be principally concerned with protecting ILF money:
- “The system is designed to accommodate the ILF financial procedures, the mind set is about protecting against fraud and the care offers are rigid and do not reflect real life. So the last person to be considered is the client. It’s a classic tail wags the dog scenario.”
- 3.34 As another respondent remarked, “the element of mistrust is getting in the way of dealing with even the simplest matter.”
- 3.35 We believe that the poor transparency of the ILF operation is a shortcoming that requires urgent remedy. Our evidence shows strongly that public awareness and understanding of the ILF is poor, and that users are often confused about their access to support. Many also have negative experiences of trying to challenge ILF decisions and are left feeling as if they are trying to

deceive the system or that they have to persuade the ILF that they ‘deserve’ more support. We agree with many users of the ILF that this is demeaning and inappropriate for a model of support in the 21st century. **We recommend that the ILF makes explicit the basis on which its judgements are made in such a way that users and their advisors are better able to predict the outcome of claims and decisions. We further recommend that the organisation reviews its training for all ILF staff in basic customer care.**

Summary

- 3.36 In this section we have explored the extent to which the ILF operates with clarity and transparency in order that people have a clear idea of what they can expect from the Fund, and what to do if circumstances change or problems arise. Our evidence points to considerable problems, and indicates that the ILF does not meet many basic expectations about the consistency of decision making, accountability for decisions made, and ensuring dignity for service users. The nature of people’s experience of the ILF is inconsistent and is heavily influenced by arbitrary factors and happenstance. We have made recommendations for changes both to improve advocacy and support for people using the ILF and to address structural and operational factors that would improve the visibility and comprehensibility of the ILF’s system and processes.

Section 4: Operational Framework: Accessibility

Introduction

- 4.1 Judging the accessibility of the ILF is of key importance since it will reflect the underlying principles and values which shape the service and its organisation. Accessibility is contingent on a number of variables. However, of prime importance are the rules and systems which determine how the ILF operates. In this section we explore whether these rules serve to be as inclusive as possible, or conversely whether they effectively exclude large numbers of potential clients either from applying in the first instance, or by acting as a deterrent because of the significant barriers to ease of access which they constitute. Accessibility differs from equity. Whereas the latter focuses upon those who are precluded from applying to the ILF, the former is concerned with the ease with which those who are eligible are able to apply and access support.
- 4.2 There are multiple factors which impact on the accessibility of the ILF; some of these are overt in their impact on ILF users (or potential users), while others operate in a more subtle manner. We begin by examining the impact of the eligibility criteria which create an explicit framework which dictates on a priori grounds who may, and who may not, be considered as an ILF applicant.
- 4.3 In Box 1.1 in Section 1 we summarised the eligibility criteria for ILF applicants. In brief, these require that applicants:
- Are living in the UK.
 - Are aged at least 16 years, and less than 66.
 - Receive the highest rate of Disability Living Allowance (DLA) or Attendance Allowance (AA) or Constant Attendance Allowance (CAA) in certain circumstances.
 - Have savings and capital of less than £18,500.
 - Expect to live independently for at least the next 6 months.
 - Must not be living in a home.
 - Must receive at least £200 worth of funding/services each week from the local authority and be assessed as needing additional care.
 - Must be in receipt of Income Support (or Pension Credit Guarantee) or have met a weekly resources test.
- 4.4 Some of these criteria have already been discussed in terms of their impact on equity principles; in this section we therefore examine the remaining eligibility criteria and how they affect accessibility. There is a particular issue with the fact that the criteria are cumulative in their impact, and it is the need to satisfy

all the aspects of eligibility which can effectively restrict access. A submission to the review by Leicestershire County Council, for example, makes the point that “users are asked to jump through a number of hoops before being able to apply for funds and then assessed again and again to receive the funds.” Moreover the cumulative nature of the criteria means that in several different respects the loss of one form of support also triggers the loss of ILF – the ineligibility ‘double whammy’.

Regards and Disregards

The ILF – DLA Relationship

- 4.5 The eligibility criteria immediately indicate the historical roots of the ILF in the social security system rather than in the social welfare world of cash for care. The explicit linkage of ILF eligibility to DLA care component entitlement is the most obvious manifestation of this. The rationale for higher rate DLA (HRDLA) operating as a gateway to ILF reflects the original intention that the ILF should focus on people with the most severe needs and disabilities. Higher rate DLA entitlement requires that:
- A person is so severely disabled physically or mentally that, by day, he requires from another person –
 - frequent attention throughout the day in connection with his bodily functions; or
 - continual supervision throughout the day in order to avoid substantial danger to himself or others;
 - And at night they to avoid substantial danger to himself or others he requires another person to be awake for a prolonged period or at frequent intervals for the purpose of watching over him.
- 4.6 The Quinquennial review recommended keeping higher rate care component DLA entitlement as the basic gateway to ILF in order to ensure that support remains well targeted. However, we received evidence indicating that this is a crude and – at times – highly inaccurate proxy for needs which is insensitive in acknowledging mental health and other needs. In particular, because DLA entitlement is biased towards physical needs and the capacity to undertake activities of daily living, this weakness is replicated in access to the ILF. Liverpool Social Services commented:
- “It is absurd that someone with severe needs and challenging behaviour should not meet the ILF criteria if they sleep well during the night.”
- 4.7 An additional difficulty arises for those people whose continuing entitlement to HRDLA is called into question, for this can lead to the simultaneous loss of two sources of income. This situation even pertains where continuing

entitlement to HRDLA is at the appeal stage. In written evidence to us the Disability Alliance has pointed out that 50% of appeals against the loss of HRDLA are successful, yet the ILF ceases to provide support during the interim appeal period. The Disability Alliance calls for the continuation of ILF payments in such circumstances pending the outcome of an appeal. We agree with this suggestion. We recognise that the 2006 Trust Deed does allow payment to continue during the first stage of DLA appeal. Nevertheless, we would wish to go further than this, and **we recommend that where eligibility for HRDLA is under review that ILF should continue to be paid until the review and appeal procedure is completed.**

- 4.8 We have already recommended that people in receipt of the middle rate care component of DLA should not be precluded from consideration for ILF funding, and we state again that we do not believe that entitlement to higher rate DLA is a sufficiently flexible or sensitive criterion to act as a gateway to ILF support. We accept that the relationship between the two benefits had a degree of internal logic when first established; however, this has become increasingly strained. The need for ILF applicants to also be in receipt of a significant amount of local authority support was introduced for the 1993 Fund, and it might be argued that this should have replaced the previous criterion of DLA support, rather than being additional. Indeed, it appears that the additional eligibility criteria established in 1993 effectively raised the threshold for applicants and created significant barriers to access for some. **We recommend that the DWP should investigate the implications of decoupling ILF eligibility from higher rate DLA entitlement, and should explore the simplification of ILF eligibility in order to remove the multiple layers of qualification that are required.** We recognise that this raises wider issues about the role of DLA and AA, and whether they should continue to operate in their current form or should be incorporated into some other spectrum of funding to support people with disabilities.

Charging and Treatment of Disability Benefits

- 4.9 Disability benefits are a consideration not only in controlling direct access to ILF, but also in shaping factors which can act as a significant deterrent to potential applicants. The way in which income from disability benefits is taken into account is a major example of this in operation.

The Treatment of Disability Benefits

- 4.10 The ILF's calculation of 'available income' is based on the premise that "users have to put some of their own money towards their care costs"¹, and the assumption is made that some of the benefits people receive "are paid to you so that you can pay for the care you need." The ILF requires half of DLA to be paid towards care costs, and for people on Income Support and receiving Severe Disability Premium (SDP), the entire amount of this must be contributed. It was evident in the course of our review that this requirement is

widely resented, and that it is inconsistent with the fairer charging approach adopted by local authorities.

- 4.11 For some service users the prospect of losing SDP and half their DLA effectively stops them from applying to the ILF, as this social worker observed in written evidence:

“It is a particular cause for concern that the contributions that a client is expected to make are high and could provide a disincentive to claim funding.”

- 4.12 The submission from Leicester City Council remarked that “the present charging policy acts as a major disincentive for disabled people to make use of the ILF.”

- 4.13 Similarly, as this service user remarked:

“I was under the impression that the ILF was to enable disabled people to be more independent. Why is it that the ILF fund takes part of my DLA (higher care component) and all of my income support? This is money which if I had, I would be more independent.”ⁱ

- 4.14 We have been told of one LA that always charges clients the maximum charge (£45 per week) and the ILF then makes an additional charge of £35 per week. In such circumstances care managers do not want to encourage use of the ILF for their clients.

- 4.15 The loss of all of the Severe Disability Premium is especially resented, with a strong view expressed to us that since this is a benefit to help towards the cost of additional disability related expenditure; it should not be regarded as available to pay for care costs. Knowsley Borough Council, for example, told us that:

“Where a person is living alone on benefits this contribution becomes too great regardless of the size of the package. This is because living costs are high, and this additional cost may make independent living unsustainable.”

Similarly, it was argued by Inverclyde Council that:

“Taking all of the SDP means that clients are left with no residual income at a time when they are being encouraged to be part of the community in which they live. We believe this leaves no funding for social activities and promotes social exclusion.”

- 4.16 As we noted in our summary of the consultation meetings, some ILF users feel strongly that if independent living is a right, it is wrong in principle that people should have to pay for the care they receive. We do not believe it is acceptable to continue taking disability benefits into account in this way, but rather than deal with these specific benefits separately we propose to address

ⁱ This comment, and some others which are quoted, reveal a misunderstanding about the contributions that are required. In fact, as we have noted above, the ILF does *not* take all of Income Support into consideration, but only the Severe Disability Premium.

the issue in the wider context of charging policies by both the ILF and local authorities.

ILF and Local Authority Charging Regimes

- 4.17 The inconsistency between ILF and local authority charging policies was seen by many respondents as a major anomaly that must be resolved. The main issue is that ILF service users experience a double jeopardy of charging and are frequently required to pay more by the ILF than they are by the local authority. Many people expressed bewilderment that their assessable income could be regarded as nil by the local authority, but that they would then face charges by the ILF. The following comments from service users make the point compellingly:

“Local authorities may allow a waiver under the Fairer Charging guidelines, or part of a waiver. Then the ILF will disregard anything in the local authority’s assessment and assume they can take away all the rest of the assessable income. This is an absolute disgrace.”

“..the assessable income is around £75 per week and my local authority says that £70 is for my disability-related costs but the ILF says that same £70 is for my care. This is nonsense, complete nonsense. How can money that has already been spent on my needs be available to contribute towards my care?”

“I have a lot of expenses connected with my disability and for many years I did not pay anything towards local authority care because I was assessed after deducting allowable expenses as having no residual income. At my last two ILF assessments, because I was not paying anything to the local authority, it was considered that all my SDP/DLA was still ‘available’. I cannot be alone in this situation.”

- 4.18 In written evidence, a respondent gave us the following vignette:

“Client X currently receives £200/week worth of care from social services and is charged £25 per week for this. They apply to the ILF and are awarded another £400 per week bringing their total care package to £600 per week. As they are on Income Support including the SDP, they will be charged £77.87 per week (ie £31.12 plus the SDP of £46.75). The ILF will reduce this charge by the £25 the person pays to social services, but their total charge (ie to ILF and SSD) will be £77.87. If this client were to receive all of the £600 worth of care from social services alone they would only pay £25 per week. It is arguable that once they have been assessed as needing that amount of care they could insist social services supply it all so their charge is lower (assuming eligibility criteria are the same which they may not be) We have had some clients who have decided not to apply to the ILF because of the above financial disincentive”

- 4.19 Clearly it must be wrong, as a matter of principle, for local authorities and the ILF to apply contradictory charging policies and calculation of assessable

income. We were also struck that it is not only service users who are concerned about these inconsistencies. Social workers and other local authority employees also expressed their concerns, for example:

“The charging for ILF or financial support offered with similar aims must be brought into line with local authority fairer charging procedures. Many of my clients have been sickened and shocked by the seemingly inflexible approach the ILF staff are forced to use.”

And as another local authority respondent remarked there is an essential contradiction in the two systems:

“A fairer charging assessment that results in the reduction of the local authority charge increases the charge the ILF have to set according to their criteria, negating any benefit to the joint support receiver.”

- 4.20 Written evidence submitted by Gloucestershire County Council similarly made the point that the fairer charging policies of most local authorities are far more user-friendly and responsive to individual circumstances. Several instances were known within the county where service users had been assessed for nil contribution by the local authority only to have to pay £70 per week for the ILF component. Not surprisingly, “this often creates tensions between the social worker and the service user.” There is also, of course, a knock-on effect for the local authority where an eligible client declines to apply to the ILF because of the differential charging regimes. In such circumstances the LA may then have to pay for the whole cost of the care package, thereby creating another source of tension – between the LA and the ILF.
- 4.21 The ILF is fully aware of these issues. In their written evidence to the review the Trustees frankly acknowledge that:
- “Our current charging structure is tough, out of step with ‘Fairer Charging’ and can lead to potential clients being unable or unwilling to accept our offers.”
- 4.22 The ILF states that charging policy is one of four dimensions along which change is required. Such changes, it was argued, should be approached “to ensure cost is least, user benefit greatest and ILF’s approach is more in line with the direction of Government thinking for disabled people.”²
- 4.23 We recognise that the guidance on Fairer Charging³ does not ensure the same charging policy is followed in all local authorities since it continues to allow elements of discretion where councils may operate more generous rules. However, adherence to the guidance has introduced greater consistency and the acceptance of some core principles which should guide charging practice. It is particularly important to note that the guidance observes that where disability benefits are taken into account as income in assessing ability to pay a charge “it is not acceptable to make a charge on disability benefits without assessing the reasonableness of doing so for each user.” We believe that this principle should also underpin the charging policies of the ILF.

- 4.24 In written evidence submitted to the review by Age Concern England, the case was made for rationalising financial assessment. In practice this would mean that the gross cost of the package of support would be established at the outset and apportioned between social services and the ILF. Social services would then apply a means-test on the basis of their charging policy and apportion the amount to be charged by both agencies. We agree that just as it is wasteful, repetitive and intrusive for ILF clients to have to undergo multiple assessments of their needs, the same applies to the assessment of their financial means.
- 4.25 It is incompatible with the promotion of support for independent living that people who apply to the ILF should be financially disadvantaged by doing so. **We recommend that by the end of 2008 arrangements should be in place to integrate the financial assessments of the ILF and local authorities. As an interim measure the charging system of the ILF should be brought into alignment with the approach of local authorities and the guidance on Fairer Charging. To avoid the double jeopardy of service users being charged twice we further recommend that the ILF should offset the amount of disability related expenditure assessed by the local authority.**
- 4.26 Such measures will have the additional advantage of meshing in with the wider move towards IBs. Early findings from the IB evaluation seem to be suggesting that a number of pilot authorities are struggling with the complexities of charges for the different income streams. The alignment of the charging regimes of the ILF and LAs will go some way towards the goal of applying one charging criteria to people on IBs.

Occupational Pensions

- 4.27 There was a strong view expressed in the evidence that taking account of occupational pensions creates a further barrier to access to the ILF. It was also argued that the treatment of occupational pensions is inconsistent and discriminatory:
- “I think it is very unfair – occupational pensions should be classed the same as wages.”
- “The financial assessment policy in respect of income from employment compared with income from an occupational pension is discriminatory against older people. Your present policy is to disregard all income from employment but to include all income from an occupational pension (i.e. postponed income from employment) as available to pay for personal assistance. This is clearly unfair and illogical.”
- 4.28 We agree that the current treatment of occupational pensions is inconsistent with the spirit of the earnings disregard, and we fail to see the justification for its continuation. In written evidence the ILF also emphasised that taking account of income from occupational pensions is “inconsistent with the earnings disregard and is a disincentive to people working.” We note that the

Quinquennial Review of the ILFs took a different line on this issue. While that review recommended that all earnings should be disregarded in ILF assessments (having particular regard to the importance of promoting incentives to enter or remain in paid employment), it was claimed that “the same argument does not apply to occupational pensions.”⁴ We do not accept this. **We recommend that occupational pensions be disregarded from financial assessment for the ILF.** We recognise that this has broader implications for other social security benefits and for the charging policies of local authorities, but we believe this is a matter of principle.

Capital Limits and Upratings

- 4.29 The savings (capital) limits which apply to the ILF have changed significantly since the Quinquennial Review. That report recommended that the ILF capital limit should be brought in-line with the savings limits applying to residential care as recommended for local authorities in the Fairer Charging guidance. This meant that savings up to £11,500 would be disregarded entirely; between £11,500 and £18,500 a tariff income of £1 for every £250 would be assumed, and for people with savings over £18,500 full charges would apply. This recommendation was accepted and implemented. However, since 2001 neither the ILF nor DWP has uprated these capital limits. The current capital limits applying to local authority services are an upper limit of £21,000 (increased from £20,500 with effect from 10 April 2006), and a lower limit of £12,750. The capital limits for residential care are automatically increased each April in order to ensure that they keep pace with inflation.
- 4.30 While we welcome the increase to the capital limits for the ILF which has occurred since 2001, we believe it is wrong that this is not uprated on a regular basis. If it is accepted that there is logic in matching the capital limits to those operated by local authorities, it follows that the same logic should apply to annual uprating. **We recommend that the capital limits on savings should immediately be brought into line with those operated by local authorities in assessing charges for residential care (and most non-residential services). This would raise the upper limit to £21,000 and the lower limit to £12,750. We further recommend that these limits should be subject to annual uprating and should continue to match the residential care capital limits.**
- 4.31 The question of uprating capital limits raises a wider question of uprating of ILF payments. In our report on the consultation events we documented the discontent of ILF users with the failure to automatically update ILF payments in line with inflation. This was also a recurrent concern in the written evidence submitted to the review. The following comments are typical of many received:

“I will have to cut my hours down due to the increase in price going over my monthly allowance from the ILF.”

“If it is possible to increase the pay rate in line with inflation annually as the local authorities do without going through the hassle of applying for an increase?”

“I am unable to provide pay rises to staff in line with inflation. The situation for some of my workers is that every year they earn less and less due to inflation.”

- 4.32 We find it puzzling that while the ILF has many characteristics which point to its historical antecedents in the social security system, the areas in which it would make most sense to harmonise ILF and Income Support are the very ones which are out of step. **We recommend that the ILF payments should be automatically uprated in line with inflation, and should follow the same index for uprating which is applied to the Income Support system.**

The Local Authority Contribution to the 1993 Fund

The £200 threshold

- 4.33 The requirement for ILF recipients to be in receipt of at least £200 worth of local authority social services support (or the cash equivalent) is a further dimension of the eligibility criteria which can significantly restrict access. As we have noted in Section 1, the origins of the £200 threshold are obscure, but appear to have been selected when the 1993 Fund was established in order to provide some proxy for a high level of support needs, and an approximate indicator of the point at which a person’s support needs might have been more ‘efficiently’ addressed through residential care. There has been no change to this sum since 1993 so the figure of £200 now bears – at best – a tenuous relationship to needs.
- 4.34 There are two opposing views on the local authority contribution, and this is an area of considerable complexity. On the one hand it might be argued (as indeed it was by some of our witnesses and respondents) that the threshold sum is too low if it is to be a criterion for targeting people with the greatest needs. Edinburgh City Council, for example, called for the minimum threshold to be increased to £350 as a means of constituting ‘the best and most intelligent use of ILF as a scarce resource’. This is an ostensibly sensible solution, but not one without difficult consequences.
- 4.35 Perhaps the main such difficult consequence is that it can be increasingly difficult to qualify for this level of local authority support, particularly in the light of the implementation of Fair Access to Care policies which have introduced an explicit prioritisation system that effectively excludes many people from local authority support who would have received it in the past. Although there is widespread support for the development of preventive services, spending pressures are forcing LAs to withdraw support from people deemed to have ‘low’ or ‘moderate’ levels of need. The ADSS⁵, for example, calculates that seven out of ten people now receive support only if their needs are ‘substantial’ or ‘critical’ and this means some people currently in receipt of an ILF/LA supported package could lose both sources of support.

4.36 In evidence submitted to us, concern was repeatedly expressed about the impact of these developments upon service users. The Leonard Cheshire Foundation argues that it creates a postcode eligibility for the ILF which it condemns as unfair. A further point made by Leicester City Council is that the requirement for the local authority to pay a minimum of £200 per week, net, towards the cost of care and not to reduce its historic contribution to the care package can be highly problematic and lead to the entire ILF award being withdrawn. A change in the service provider used by a local authority can also affect their contribution simply because of different prices, which “can inadvertently cause the contribution to fall, and gives the impression that the authority is failing to meet its commitments, and take considerable time to resolve.”

4.37 The question of whether the ILF is properly targeted is evident in the following comment:

“The question is whether it is the most effective way of achieving what it set out to achieve which was helping the most severely disabled people. I think there has been a lowering of the eligibility threshold from what was originally intended – so are we still reaching those it was intended to?”

4.38 This raises the matter of whether the role of the ILF has actually changed over time and whether different criteria now need to be applied to judge the appropriateness of ILF targeting. As this respondent argued, for example, a case could be made for supporting those who don’t receive this level of funding from the local authority:

“The people who are not in receipt of at least £200 worth of day respite are unable to claim; to my mind these are the ones who need it! An example is one family that I know of where the daughter no longer attends a day centre for the simple reason that the shake-up of social services just doesn’t suit her (quite honestly the service here is unsuitable for several of the clients). This family have their daughter home all the time now and as they get older it is harder on them and their daughter. I think these are the people who need the support of the ILF.”

4.39 Similarly, other respondents commented on the impact of the £200 requirement and the dissatisfaction they felt in having to use unsuitable services merely to be able to qualify for the ILF:

“X attends an Adult Resource Centre where she spends her day in a quiet room with a small group of profoundly disabled people. It is not very stimulating for her. The Centre is continuously understaffed and I would really prefer not to send her there. But she would not get ILF if she did not attend.”

4.40 This issue also arose in our consultation meetings. As we remarked in our report, it is apparent that some people are obliged to use poor services (particularly day care) which they don’t want and which they would not choose, but without which they would not qualify for the ILF. We encountered this as a particular issue in Northern Ireland where people reported that the option of receiving a Direct Payment in lieu of services was not available, and people

were therefore forced to use poor quality and inappropriate services which were of little value or help to them.

- 4.41 We understand the principle of partnership between local authorities and the ILF which is enshrined in the £200 minimum contribution from the local authority. However, we have grave concerns about how this can impact on ILF users (and potential users). This is a perverse and unintended consequence of the original requirement and it needs to be addressed.
- 4.42 The respective contributions of the ILF and the local authority raise wider issues about the purpose of the ILF overall. If this is an extra fund to provide support for people with exceptionally high levels of disability who require more support than the local authority can provide, then it can be argued that the £200 threshold should be raised significantly. Moreover, if the existence of the ILF simply allows local authorities to provide a minimum level of support in the knowledge that they can be subsidised by the ILF effectively ‘topping up’, this is a further argument for raising the threshold. At the same time, obliging people to use inappropriate services simply to hit the required threshold for ILF eligibility is a poor use of resources and fails to address the best interests of clients.

Higher Local Authority Contributions

- 4.43 The £200 contribution from local authorities is the minimum amount that they must make. At this level, the ILF input can be up to £375 (i.e. a total package value of £575 per week). If the package cost is £625 the local authority must contribute £250 a week, and beyond £625 the contributions are matched on a ‘pound for pound’ basis. We have already discussed earlier in the report the effect of the maximum sum of £785 (from Local Authority and ILF contributions) which cannot be exceeded for the first six months of a package, and which effectively precludes some people with very high level needs from applying to the ILF in the first instance if no other funding sources are available. We find these various limits and rules around respective contributions highly complex, and somewhat arbitrary. Moreover, they can have a significant impact on service users. As one person memorably remarked to us in a consultation meeting, matching funding £ for £ “means you get caught in the middle of a three-way argument.” It is unacceptable that the rules governing ILF and local authority contributions should have a detrimental impact on ILF users in this way.
- 4.44 One improvement would be to make FACS eligibility the trigger for eligibility for ILF – a change that would eradicate the restrictions on personal care and domestic assistance that currently surround the nature of the LA contribution. However, this could still leave many people outside of ILF as a result of the increasingly tight use of FACS criteria. Alternatively it was suggested to us by West Lothian Council that we should consider setting a minimum percentage of the cost of the package to be provided by the LA rather than fixing a specific sum – a measure that would help to address the problem of varying care costs around the country.

- 4.45 Whilst there is an attractive logic in simply proposing that the £200 limit be increased to at least catch up with the rise in costs since 1993, we are also mindful of the changed circumstances in respect of the introduction of FACS and the tightening of access to LA support. An increase in the £200 limit may simply have the effect of removing from LA help many people currently receiving ILF support, or people who would in the past have been expected to receive such support.
- 4.46 We believe there are some fundamental tensions and contradictions surrounding the objectives of the ILF which have been exacerbated by the changing context of local authority social services responsibilities. The idea that ILF should be targeted on people with the greatest needs over-simplifies the position. This would be an easy objective to promote if we could assume that people with lesser needs would automatically be the responsibility of social services. However, this is far from being the case. The introduction of FACS has meant that local authorities are increasingly restricting their responsibilities to people deemed to have ‘critical’ and ‘substantial’ levels of assessed needs. At the same time, social care policy is emphasising the importance of prevention and early intervention, and this objective is in clear tension with the FACS prioritisation. We are extremely reluctant to recommend a raising of the eligibility threshold of the local authority contribution since this could exclude significant numbers of people from ILF entitlement, with no guarantee of their needs being met elsewhere.
- 4.47 **We recommend that the local authority contribution should remain at £200.** However, we find the current arrangements on the higher LA contributions and the ‘£ for £’ rule to be confusing and cumbersome. A much simpler approach would be for the ILF and LA to agree to a percentage contribution that reflected their respective input. It has not been possible for us to state what that cost distribution should be, but **we recommend that the ILF and its LA partners examine existing data on the cost distribution of care packages and determine a fair percentage cost allocation for total package values in excess of £575 per week.**

Application and Review

- 4.48 The final set of issues which affect the accessibility of the ILF are not to do with the eligibility criteria, but with a range of process factors associated with application to the fund and review of circumstances. We have already addressed many of the issues around financial assessment, and we have made recommendations for removing the worst aspects of duplication and overly intrusive processes. However, there are other matters which also need to be tackled if the ILF is to be as easily accessible as it can be.

The accessibility of the organisation

- 4.49 Increasingly the public face of any organisation is judged not just through its printed materials and the manner of its employees, but also by its internet and email profile. We understand that many ILF users may be less likely than the public overall to have access to or familiarity with computer technology; however, this makes it all the more important that when such contacts do occur they are easy to manage and satisfactory.
- 4.50 The ILF website is neither particularly accessible nor user-friendly. It takes considerable time and effort to locate the right information, as several respondents remarked to us. Font sizes are small and the lay-out of the site is cumbersome, features that are all the more surprising because we understand that a major redesign of the website took place during 2005/06. **We recommend that the ILF revisits the design and appearance of its website and in consultation with a wide group of ILF users it initiates a comprehensive redesign which has regard to best practice in web design in general and to principles of accessibility in particular.**
- 4.51 In the course of our consultation meetings various comments were made about the shortcomings of information. For example, we were told that the ILF information pack is “a waste of paper – poor quality and repetitive” and that it is “not user-friendly, dull and too heavy with text.” Again, we understand that during 2005-06 the ILF undertook a review of all the fund’s external literature, to improve the accessibility of information. New literature is being introduced during 2006/07. We acknowledge and applaud the efforts that the ILF has made in making its publications available in a range of formats, including large print, Braille, audio and other languages. **However, we believe further improvements are required and urge the ILF to reconsider its literature review and to test out with sufficiently wide and diverse groups of users whether it has succeeded in improving accessibility and what – if any – refinements are required.**

The Application Process

- 4.52 The process of application is an important test of the accessibility of any benefit or service, and some people expressed satisfaction with the performance of the ILF in this respect. One person acting as appointee for a relative stated that:
- “The ILF is the most superior cash for care model. On contacting ILF the social worker is with you inside 14 days and an assessment is carried out. If all parties are agreeable recommendations are given by the ILF social worker and within eight weeks you are up and running.”
- 4.53 Not everyone has had such a good experience. Some people, for example, were dissatisfied with the sheer complexity of the application form. Medway Council claimed that the form “can appear daunting and be perceived as difficult”, whilst Middlesbrough Council described it as “intimidating.” A much

more common complaint, however, was the length of time taken to process an application. In our summary of the findings of the user consultation events we noted that:

“In several meetings people commented on the slowness of the initial process in applying to the ILF. There could be considerable delays between contacting the ILF, having the assessment conducted and receiving any payment.”

- 4.54 In written evidence, Leicestershire County Council told us that the lengthy application process was ‘a major weakness’ of the ILF with up to six months passing before successful completion. They note that:

“People with long-term conditions may see a significant change in their circumstances during this time and so need re-assessing – the process begins again.”

- 4.55 Difficulties can be especially evident with complex cases where a number of funding streams need to be synchronised. We were told by the Brain Injury Rehabilitation Trust, for example, that:

“We believe the weaknesses are that the application process is lengthy (and therefore not timely in terms of being available when our Service Users are ready to move in to the community) and too complex. In particular, when Service Users are moving into supported housing projects, where Housing Benefit and Income Support also need to be arranged, the complexities of getting the ILF funding to fit along with the fees for the remaining support costs are considerable.”

- 4.56 Experiences of applying to the ILFs are mixed, but it is clear that acceptable standards are sometimes not reached. **We recommend that the ILF sets itself a target of a maximum of eight weeks from the date of application for reaching a decision on an initial application for support. Where it is not possible for this target to be reached then clear explanations should be given to the applicant.**

The Review Process

- 4.57 ILF clients generally have a review of their circumstances every two years. Anyone can request a review to take place at an earlier date if their situation changes significantly. The timing of review needs to be considered; reviews which are too frequent are bureaucratically cumbersome and wasteful; but at the same time too long a gap between reviews can also be far from ideal and can place too much onus on the service user taking the initiative to request an earlier review. Moreover, given that the ILF is intended to be targeted on people with a high level of complex needs, instability and frequent change in condition are likely to occur frequently. It would seem logical that the review cycle for the ILF should be comparable to that which is followed in social services, and **we recommend that all ILF clients should be reviewed at least annually and more frequently if the need arises.**

4.58 The actual review process followed by the ILF was generally commented upon favourably, and this reflects the positive experiences which many ILF users report of the ILF Assessors (ILFAs) who generally approach assessment and review in a friendly and accessible manner (“personable, approachable and very professional”). This conversational approach was often compared with a more ‘tick box’ experience of local authority social services. As an ILF user remarked at one of the consultation meetings, ILFAs are “people-people, not paper-people.” Continuity of ILFAs from one review to another was seen as particularly helpful.

4.59 There are shortcomings of the review process however, and these are associated particularly with the length of time that it can take for a review to be processed, and to the fact that increased payments are not back-dated to the date of request for review. These comments from respondents make the point:

“The application and review processes are complex and take a long time. This can cause particular problems for service users whose situations are unstable and whose needs change. By the time the award has been made, the hours of care and/or the providers’ costs may have changed.”

“In 2004 I had an ILF review which took 30 months to complete due to a whole host of issues about how the review was being conducted.”

4.60 Coordinating the reviews with social services is also problematic at times, and some social workers who submitted evidence to the review identified such frustrations, for example:

“As a social worker I am asked to complete the SSD1000 form and send it off to Nottingham well in advance of the ILF review. Therefore I always do this. When I get to the ILF review, the ILF Assessor always asks me where the ILF form is!”

4.61 The SSD1000 form was a source of considerable discontent to some LA staff. The London Borough of Hammersmith and Fulham told us that the form, which relies on facsimile transaction, is “poorly designed and unprofessional.” Specifically it was said that the proforma cannot be completed online, does not fit LA files (A4), is user unfriendly and depends on small, neat and straight line handwriting to make it legible.

4.62 Leicestershire County Council similarly told us that the review process was “problematic”:

“Workers were contacted who no longer care managed the case, the review process is too closely linked to the application process re financial assessment. Changes in DLA benefit could lead to funds being withdrawn immediately. The review process is not synchronised with that of the LA and cases where packages become unstable, informing the ILF about changes was impracticable and unworkable.”

- 4.63 Just as we have recommended that there should be integration of financial assessment procedures between the ILF and local authorities, it follows that this should also apply to review processes. As many respondents remarked to us, it is inefficient and cumbersome for there to be multiple layers of review. For example:

“Considerable costs are also wasted by the seemingly constant need for all the agencies to carry out regular reviews (...) I fail to see why all the separate agencies need to have separate reviews in order to keep going over the same ground, when each of them has all the details to begin with.”

- 4.64 We believe that many of the difficulties experienced with ILF review would be overcome by a rationalisation of the process and a removal of duplication. **We recommend that in agreeing how best to manage shared financial assessment processes, the ILF and their local authority partners should also address how to jointly manage reviews. We further recommend that all documentation associated with applications and reviews should be simplified and able to be completed online.**

Summary

- 4.65 In written evidence to us, In Control conclude that:

“Although the ILF has worked hard at making its systems transparent, the inevitable complexity of a system which is both highly rule bound and then intimately connected to LA systems that do not work to the same systems and can vary from place to place means that the ILF cannot be considered an easy-to-use system.”

- 4.66 We agree with this judgement, and in this Section we have addressed multiple dimensions which compromise 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, and we have addressed the anomalies - which were identified time and time again in the course of the review – between the way the ILF operates and applies its rules, and the approach of the local authority. We believe that in the best interests of service users it is essential that these inconsistencies are tackled urgently; it is wrong that individuals should have to understand and adhere to different operating systems and cope with all the accompanying confusion, bureaucracy and stress. Some of the wider impediments to accessibility reside in the duplication of functions between the ILF and social services and we have recommended accordingly that these should be resolved by a move towards integration of the key processes of application and review.

- 4.67 We will return to questions of openness and accountability in Section 9 of the report, and we will explore some of the dimensions of accessibility which arise in that context.

References: Section 4

¹ Independent Living Funds (2006), Leaflet 4: *How your offer is worked out – if you do not get Income Support*, and Leaflet 5: *How your offer is worked out – if you are on Income Support*.

² Independent Living Fund (2006), *Submission from the ILF to the Review Team*.

³ Department of Health (2003), *Fairer Charging Policies for Home Care and other non-residential services. Guidance for Councils with Social Services Responsibilities*.

⁴ Department for Work and Pensions (2001), *Independent Living Funds, Quinquennial Review 2001*, para 79.

⁵ Williams, A., Presentation at 'Getting to Grips with the Money Launch', April 2006.

Section 5: Operational Framework: Self-Determination

Introduction

5.1 Ideas about the individual's capacity to formulate and act on plans and purposes that are self-determined feature as a foundational concept in most theories of rights and have become an explicit goal of the disability movement. Self-determination is about making personal choices, and this means not only the removal of barriers to self-determination, but also the provision of that assistance which makes self-determination possible. For Morris¹ this concern echoes the concept of 'autonomy' in the citizenship literature – the ability to determine the conditions of one's life and to pursue one's life projects. She accordingly identifies three crucial messages that are relevant to the citizenship of disabled people:

- a need for support to make choices does not mean that someone cannot experience self-determination;
- in order for disabled people to have equal opportunities to be full citizens it is necessary to take action to remove barriers to self-determination and, for some disabled people, it will be necessary to use resources to support self-determination;
- the action to be taken must be determined by disabled people themselves.

5.2 We find these messages persuasive and they will underpin our judgements in this and later sections of the report. We examine the issue of self-determination under three key headings:

- life planning
- assessment and self-assessment
- resource allocation

Life Planning

The Life Planning Concept

5.3 Even if individuals know how much funding they are entitled to use, they may still need help in deciding how to use that resource – in other words they may need resources to support self-determination. The main issue here with cash for care programmes concerns the extent to which they are simply conduits for cash payments, or whether they also take some responsibility for supporting people with the ways that payment is used. In the evaluation of the first phase of In Control² the following five areas of 'life planning' are identified as important.

- **Personnel** services: help to recruit staff, arrange training or staff management; advice on contracting and employment law and good practice.
- **Finance** services: help with payroll, keeping accounts and making financial reports.
- **Insurance:** cover for Public and Employer's Liability or as a means of putting aside money for emergencies or periods of higher need.
- **Management:** help to supervise, coordinate and organise personal assistance.
- **Brokerage:** help to plan support, to find and recruit sources of support, and change services when required.

5.4 Responsibilities such as these can be formidable, and studies into barriers to take-up of direct payments across the UK ³ have all found that difficulties in finding Personal Assistants (PAs) and anxieties about organising their employment have been high on recipients' lists of challenges. Furthermore there is evidence ⁴ that the systems that are most appreciated by recipients are those which safeguard their self-determination, are linked to a clear brokerage strategy and are routed through organisations of disabled people, rather than through the providers of the cash payment.

ILF Policy and the Views of Service Users and Partners

5.5 The current position of the ILF in respect of support for life planning is at best minimalist, with no personalised follow-up support and an allowance of up to only £10 per week (raised to £12 from October 2006) available for the cost of payroll, administration and associated costs. Some users were unhappy with such a small weekly amount:

“When a bookkeeper is included on an ILF care package it is usually because the family do not want the hassle of running an ILF care package. This can remove a lot of the worry. A bookkeeper is often used to run the whole ILF package and this needs to be paid at more than £10 per week.”

5.6 This policy seems to derive from ILF custom and practice rather than from any restrictions arising from the Trust Deeds or COGA, and it seems that the ILF is aware of the limitations of this approach and the problems that can ensue. In written evidence to this review it states that:

“Our users have told us that simply transferring responsibility to vulnerable people without adequate support can create new stresses, and our system assumes rather too readily that funding alone empowers people.” ⁵

5.7 The evidence gathered from our own consultations with ILF users plus the written evidence submitted to us would certainly confirm the judgement of the ILF, and raises the issue of why a serious examination of the problem has not

been previously undertaken. In our summary of views arising from the consultation meetings we noted:

“One area of difficulty which was highlighted in all of our discussions concerned the need for support in managing the ILF. Some users of the ILF take on the responsibilities of being the direct employer of PAs, while others pay an agency to manage this side of things on their behalf. Managing an ILF budget and understanding the responsibilities of managing a pay roll and associated tasks can be very demanding, particularly for people who may not have had previous business experience. Many ILF users told us how difficult it had been – especially when they were first getting started – to understand what they had to do.”

- 5.8 Very similar points were made again in many of the written submissions we received. We were told by Rotherham Council, for example, that:

“Service users get little help with managing their money or recruiting and training staff. This is a major concern as highly vulnerable people are not having support workers police checked or trained in moving and handling.”

Again, in written evidence, a service user commented of the ILF position:

“They are happy to give money over to pay for care but they are virtually completely unable to offer any kind of support, for example about employment responsibilities. They just wash their hands of it.”

- 5.9 This can, as another service user pointed out, have knock-on effects for costs:

“By making the award recipient responsible for organising the arrangements he or she becomes a private customer. I know that the charge to me is at least £2.56 an hour more than they would charge social services.”

- 5.10 This situation was frequently contrasted unfavourably with that of direct payments where local authorities are required to ensure that people receiving payments are also offered practical support to make effective use of the payment. This in turn gives rise to further anomalies. Those people solely in receipt of ILF cannot expect any ‘life planning’ support (a circumstance most likely to apply to those in receipt of the Extension Fund) whereas those ILF users also in receipt of a direct payment may be able to access at least some such support in relation to the latter payment.

- 5.11 In practical terms it is absurd for a local authority to provide life planning support only for the direct payment element of a combined ILF/DP package, and this has resulted in LAs often taking on a default responsibility for supporting ILF users. We discerned considerable resentment on the part of LAs to this unilateral ‘cost-shunting’, especially since the ILF is not even prepared to count any expenditure thus incurred towards the £200 contribution threshold.

“ILF is advertised as a tripartite agreement between the fund user, LA and the ILF, but this can often feel like an unequal balance whereby the LA carries most of the risk.” (London Borough of Barking and Dagenham)

“It often feels as though local authorities end up supporting clients with PA issues when things go wrong.” (Sheffield City Council)

“Far too often we have had to provide intensive support for people who have been using ILF with little or no support or guidance about managing or employing a PA.” (Kent County Council)

5.12 In evidence to us, the ILF itself expressed a wish to engage with life planning in a range of ways:

- to pay automatically rather than on demand for the statutory employer related costs like holiday pay and National insurance;
- to consider widening the scope of cover for redundancy payments;
- to assist with other relevant non statutory costs in a more proactive way e.g. legal costs for contract advice; employment and training costs;
- a new role for the ILF in supporting clients to employ personal assistants in line with legal requirements and best employer practice, including payment for advertising recruitment and training costs.

5.13 We agree with the ILF that these goals should be funded and pursued, and we welcome a review introduced by the ILF in December 2006 to produce by the end of May 2007 recommendations to Trustees for improvements to the support and advice given by the ILF to its users in their roles as employers. However, we also find it surprising and disappointing that hitherto the ILF appears to have given the issue so little recognition. **We recommend that the ILF urgently develops a strategy for supporting life planning for all of its service users, but that this be undertaken in partnership with local authorities and independent brokerage support organisations rather than separately.**

Other Life Planning Models: Local User-Led Centres for Independent Living

5.14 The development of local user-led Centres for Independent Living (CILs) is now an important part of long-term Government strategy for the support of disabled people. The Life Chances report ⁶ recommends capacity building in existing user-led CILs and the development of new CILs, with the specific recommendation that by 2010 each locality should have a user-led organisation modelled on existing CILs. Moreover, in the joint protocol between the Association of Directors of Social Services and the National Centre for Independent Living (NCIL) ⁷ it is acknowledged that there is a clear correlation between direct payment support services controlled and run by disabled people, and successful implementation of a direct payments strategy. Some of our respondents were keen to highlight the advantages of this sort of local support as compared with the centralised bureaucratic model felt to characterise the ILF:

“When you hear some of the people at senior levels within ILF talking, their interest is organisational – protection of the organisation as opposed to outcomes for the end user. You can see a much more attractive model which is about actually getting some of the user-led organisations to work in partnership with other organisations to deliver the same things, but with a different set of incentives, because their incentives will naturally be around best quality service provision to the end user. Which I think you could never create with an NDPB because those are at one remove from the experience.”

“The agenda here is actually about people being local citizens in their local communities, and the point of funding from these various sources and packages is to actually enable people to be equal citizens and to take opportunities in their local area. Removing the funding responsibility to a national body has dangers in that it creates a boundary between this national funding body and local resources for non-disabled citizens.”

- 5.15 If the Individual Budget model is rolled out then the need to develop additional support capacity will be even greater, and some of the IB pilot sites are already looking at the feasibility of an advocacy service to support people with their planning. However, it appears that one of the problems identified in some IB pilot sites is that of actually accessing people and organisations who can offer skilled support in developing plans and commissioning support. The fragility of this market has been seen recently with the collapse of the London based charity Choices which had support planning contracts with eight local authorities, and in the reported financial difficulties at NCIL. If independent user-led brokerage models are to emerge in a timely way then there will have to be rapid progress towards the 2010 Life Chances target for local CILs.
- 5.16 In the meantime, the ILF has itself signed up to a joint protocol with NCIL. This has not been an easy agreement to write since the two bodies are fundamentally different – NCIL is a lobbying and action body representing disabled people, whereas the ILF is an agency of Government. The protocol is understandably cautious and does not go much beyond a commitment to sharing information and ideas, and whilst this is an important first step we do not believe it goes far enough in the new user-led context. **We recommend that the Government’s commitment in the Life Chances report to creating a user-led organisation modelled on existing CILs in each locality by 2010 be firmly implemented, and that the ILF builds upon its existing protocol with NCIL in order to assist the development of capacity building of CILs. This exercise should be undertaken in partnership with local authorities so as to avoid duplication of support for those in receipt of both ILF and Direct Payments.**

Assessment and Self-Assessment

The Assessment Dilemma

- 5.17 The way in which potential users are assessed for support is an important influence on self-determination. The ways in which individuals are assessed for 'cash for care' programmes, and indeed for other care services, is complex, and goes to the heart of the debate on user empowerment. This is a point that has been forcefully made by Jane Lyon, a service user, in a critical analysis of direct payments⁸ in which she emphasises that cash payments are only a mechanism for providing social care, and are a potential outcome from the assessment process; it is the assessment process itself that is the key decision point for determining how much social care, if any, will be provided to a claimant. She approvingly quotes the argument of Stainton⁹ that the role of the local authority (or in this case the ILF) is not to define what a person's needs are or how they are to be met, but to negotiate with the individual what needs are legitimate claims against the state, and to support the person in meeting those needs deemed legitimate in ways that are acceptable to them.
- 5.18 The problem with relying solely on professional assessment has been highlighted in a recent research project into the role of professional assessment in personalised care for adults with disabilities, in which Foster et al¹⁰ reveal the variability among practitioners in how they collect information and determine the kinds of topics to be explored during the assessment process. Inevitably such processes are shaped by the constraints of the organisational context and broader service environment. The authors note that:

“Some practitioners documented only those needs that they perceived could be met within the current service environment...It cannot be assumed that practitioners are not self-interested, given that their efforts must produce something useful or acceptable to the organisational and policy environment to ensure continued support and survival.” [p133]

ILF Users and Multiple Assessments

- 5.19 Given that ILF applicants to the 1993 Fund also have to be in receipt of £200 of relevant services or support from their local authority, they immediately face the problem of a dual assessment from the ILF and the LA. Indeed, since eligibility for the higher rate of DLA is also a condition for eligibility for ILF, then the likelihood is that ILF users will have been through three application processes and up to three assessments by three different agencies working to different eligibility criteria but all for the same purpose – the promotion of independent living in the community. We found considerable discontent with this state of affairs and much support for the idea of streamlined assessment. LAs were unhappy that the ILF was not prepared to accept its own assessment. Coventry City Council told us:

“Service users felt that having a second assessment by an ILF assessor added to the number of people involved in their lives and felt this was unnecessary. There was a strong consensus that local social workers should be able to access the fund on their behalf.”

5.20 In similar vein the London Borough of Brent stated that:

“ILF creates unnecessary duplication in that it goes against the whole principle of a single assessment. Running two similar schemes does not make financial sense.”

5.21 And as a final example, this comment from a service user was typical of many we received:

“I fail to see why all the separate agencies need to have separate reviews in order to keep going over the same ground when each of them has all the details to begin with.”

5.22 On the other hand we also heard during the consultation events from service users who much preferred the experience of an assessment from the ILFA rather than the LA social worker, which raises the issue of the desirability of the ILF taking the lead on all assessments for ILF and DPs.

5.23 We agree that the current situation is wasteful and unduly intrusive into people’s lives. We are also aware that the ILF has looked carefully into the possibility of either the LA undertaking an assessment for the ILF, or the ILF doing so for the LA, and has arrived at pessimistic conclusions in terms of what can be legally permitted or reasonably achieved. The current Trust Deeds do not give an express power for the ILFs to offer other services like assessment to a third party, and the ILF view is that there is a risk to the obligations of the Trustees if the LA is undertaking the assessment role on behalf of the ILF. Moreover, the ILF feels that the information sought by its own social workers and the LA social workers is often qualitatively different, therefore there is unlikely to be any saving produced by asking the social worker to do an assessment that then needs to be checked by ILF staff.

5.24 We do not regard this continuing state of affairs as acceptable. Even if, under current rules, a further check by ILF staff might be necessary, there should still be scope for a reduction of the assessment burden on ILF applicants themselves. However, more fundamentally it cannot be in the interests of service users, service agencies or the taxpayer to continue with the existing situation. The 2001 Quinquennial Review recommended “that the ILFs study the LA/NHS Single Assessment Process procedures to identify whether there is scope to introduce some such procedures in their dealings with some or all LAs.” We can find no evidence to suggest that such a study has been undertaken, but the advent of the In Control framework for IBs offers a fresh window of opportunity that must be grasped. **We recommend that only one assessment for ILF applicants be undertaken. It is for the ILF and its partner agencies to identify the most appropriate way in which this can be achieved, and we suggest that this recommendation be fully implemented by the end of 2008.**

Self Assessment

- 5.25 A system of self-assessment constitutes a more radical way of addressing the problem of multiple assessments and could well constitute a more appropriate long-term strategy. There was strong support for exploring the scope for self-assessment following the consultation on the Independence, Wellbeing and Choice social care green paper, and in the White Paper Our Health, Our Care, Our Say the Department of Health committed to introduce a new common assessment framework, which would include enabling people to self-assess where possible. The Department of Health subsequently committed itself to exploring the scope for improving needs assessment processes, including the use of self-assessment and assisted/mediated assessment to support people to identify risks to their own independence which could then be addressed by minor equipment, adaptations or services. Expressions of interest were invited to establish pilots starting in July 2006, and running for 10-12 months, with the aim of determining whether, and in what ways, viable models of self-assessment can be applied to services on a large scale and support significant numbers of people.¹¹
- 5.26 Eleven pilots have now been launched to explore self-assessment for people with long-term needs and enabling people to self assess their need for support from a range of services, such as equipment, home care, standard housing adaptations and low-level preventative services. Announcing the pilots, Social Care Minister, Ivan Lewis said:
- "Self assessment has the potential to give patients and service users much greater control over their care and faster, easier access to services. This is central to our vision for the future of health and social care."
- 5.27 These pilots, launched in October 2006 and running until 30 September 2007, constitute an important and radical alternative to traditional conceptions of professional assessment as the gateway to resource acquisition. More importantly for the future operation of the ILF, they also form an important initiative alongside In Control and the IB pilots. In the case of the latter most of the sites have developed variants of the In Control self-assessment questionnaires, and service users are completing the forms with help from their care manager, support worker, family or friends. Some sites, however, still regard self-assessment as too risky, especially for older people.
- 5.28 We understand that this is a contentious and complex development. In the IB pilots there is a fear that users may 'under assess', and in some cases both the user and the care manager are filling out separate assessments and then comparing the outcomes. Clearly the local CILs to which we refer above would have a vital role to play here, for it will be very difficult for users who are accustomed to 'being assessed' to suddenly think outside of traditional boxes. Nevertheless, it is difficult to see how self-determination can become a reality without self-assessment, and we expect that the logic of the IB concept, along with the evidence gathered from both the self-assessment pilots and the IB pilots will result in a further and substantial shift towards self-assessment over the next two to three years. The ILF cannot stand apart from these developments. **We recommend that the ILF develop its own strategy for**

promoting a culture of self-assessment amongst its users and that it plays a full part in both the self-assessment and IB pilots.

- 5.29 Self-directed assessment clearly also implies huge changes for those currently undertaking professional assessments – both local authority care managers and ILFAs. Both of these groups currently act as intermediaries between the individual and the state in terms of adjudicating claims for support and, to some degree, influencing the extent and nature of such support. Some people believe that the current conflation of roles is unsustainable. According to Dowson: ¹²

“Care management involves two different kinds of task. One task concerns rationing taxpayer’s money – deciding whether someone should get help and how much help they are entitled to, in services or money. The other task concerns helping people to achieve the kind of life they want for themselves. Both these tasks are very important, but they do not comfortably fit within the role of the same person.”

- 5.30 There is a view that some care managers and other assessors would welcome the opportunity to be relieved of the rationing element of their role, thereby enabling a return to ‘traditional social work’ - helping people to organise their lives through brokerage and advocacy activities. ^{13 14} However, the ‘navigator’ role need not be a social work role; it could be fulfilled by a variety of people or organisations, including voluntary groups, CILs and information specialists. ¹⁵ Developments of this nature clearly have important implications for the current ILF Assessors, and thought will have to be given to the ways in which the ILFA role may need to change and how the skills of ILFAs can be utilised in such new arrangements. **We recommend that as part of its strategy for promoting a culture of self-assessment as suggested above, the ILF undertake a preparatory review of the role and function of ILFAs in a system of self-directed assessment.**

Resource Allocation Systems

Current Dilemmas

- 5.31 It has been noted that in the present system, resource allocation flows out of professional care planning. Decisions are typically subject to two kinds of rationing. First, criteria are applied to determine initial eligibility for support and then a professional judgement is made on what constitutes a ‘fair service’ within existing resources. This throws up some dilemmas for cash for care models which are essentially founded on principles of user-empowerment but which seek to balance this with some control on eligibility for the scheme and some control on resource availability. Given legitimate limitations on resource availability it is not feasible to remove eligibility thresholds entirely, but organisations of disabled people have argued that within this constraint, outcome-focused assessments based on self-assessment of needs should replace bureaucratic and intrusive investigations.

- 5.32 The driver for change here is the proposal coming from the In Control programme and the Individual Budget concept that the resources that are available to individual people with disabilities for use as an individual budget, and the mechanisms by which those resources are to be calculated, should be more transparent. In a system of self-determined [or at least self-directed] support, the grounds for allocating resources must be transparent and people must know their available funding before they begin to plan how to use it. The most practical proposal for reconciling self-determined needs with the inescapability of rationing is the notion of a Resource Allocation System [RAS] along the lines developed through the In Control programme¹⁶.

The Resource Allocation System (RAS) Model

- 5.33 In outline the RAS uses a self-assessment questionnaire to gather information about a person's needs, and then identifies the appropriate level of funding to match them. The goal is to tell disabled people as quickly as possible how much money they will have available to spend on their own support – a process that begins with a calculation of how much money it is 'reasonable' to spend on an individual with certain kinds of need. The concept of 'reasonableness' is important because this is the link between self-determination and rationing; a process that is fair and transparent to the disabled person, but affordable for the funding agencies. RAS models have been developed with the In Control pilots by means of four steps:
- identifying the price of major, typical service elements;
 - identifying typical service packages;
 - examining the price and distribution of typical packages;
 - determining funding for the existing system on to which assessment criteria can be mapped.
- 5.34 Three criteria have been used – levels of need (low, medium or high), family situation (living in family home or not) and complexity (yes or no), giving rise to twelve possible permutations. There are currently four versions of RAS, each incorporating learning that has been gathered from use of the previous version. Version 4 is based on establishing a local 'price point' – an amount which, when multiplied by the points scored on a self-assessment questionnaire, produces the individual allocation. The key change from traditional practice is that the RAS enables clarification of the financial position much earlier in the process, and therefore allows the care plan to be developed as close to the person as possible.
- 5.35 Most of the IB pilot sites have been using one of the RAS models as their starting point, and it is a change with huge implications for social care generally, and for the ILFs in particular. The current operational framework of the ILF does not fit comfortably with the RAS approach because of the need to divulge much more information than would be expected with the self-

assessment basis of the RAS, and also because money is accessed only after a care plan has been determined and agreed by the ILF. Some of the evidence submitted to us made this point strongly. Warrington Borough Council told us:

“To work with individual budgets it would be necessary for agreement to be reached on the amount of funding available from ILF at an early stage. The difficulty is that brokers or others supporting people with individual budgets need to know how much money they have to spend in order to put together a plan, but currently ILF can only be claimed when a clear care package has been agreed and a start date is known.”

- 5.36 We are aware that the RAS is still at an early stage of development and that further work needs to be undertaken before it can become a robust model to underpin self-assessment. In particular there are issues to be resolved in respect of how costs or shadow prices are estimated, especially in the case of in-house services, and we expect the IB pilots will help to identify problems and opportunities. We appreciate also that these developments are not taking place in isolation from the ILF but in partnership with it, since ILF funding is one of the income streams in almost all of the IB pilots. Moreover we have been told that ILF has cooperated closely with the In Control programme and we are aware of the Pilot Protocol that has been agreed between the ILF and the In Control Programme.
- 5.37 It is encouraging to learn of the willingness of the ILF to engage with the emerging agenda on RAS and we would urge the ILF to continue to be a strong partner in this programme. However, there are some fundamental differences of culture and approach which, unless addressed, will make substantial progress unlikely. We would like to see a root and branch examination of the compatibility between the current ILF operational framework and that required for an effective RAS. **We recommend that ILF uses the opportunity offered in the IB pilots to develop – in conjunction with In Control and the CSIP Implementation Support Team – a strategy for identifying the obstacles to adopting the RAS model and what will need to be in place for these to be addressed. The presumption must be that the RAS model is the desired way forward, and that the ILF income stream be fully incorporated into the rolled out IB programme.**

National or Local RAS?

- 5.38 A critical issue in respect of RAS is that of the extent to which central government is prepared to take responsibility for equity in the provision of social care support. Given the existing evidence of local variability, especially in relation to direct payments, it is necessary to determine whether there will be one national RAS or, potentially, 150 local models. Reflecting upon the experience of the IC pilots, Duffy¹⁷ is clear that a lead is needed at central level:

“It is clear from discussions with local authority leaders that they are very aware that they cannot sensibly define such a framework in isolation from each other or from central government. It is vital therefore that central government takes a lead role in shaping the resource allocation framework.”
[p7]

5.39 A nationally set RAS would be more consistent with the current situation of the ILF which itself operates at a national level, and it would begin to address the problems of lack of portability and undue local variability of support. In Control is of the view that the latest version of its RAS does offer a potential national framework for resource allocation, and that it is applicable to both working age adults and older people. Such a model would need to consider also whether RAS would supersede or be integrated with FACS, with the possibility that FACS would then become part of a system that rations resources directly. Currently FACS should ration eligibility for support before the question of rationing resources arises, and it may be that a national RAS could provide local authorities with enough information to allow them to make eligibility decisions against their FACS threshold. It may also be possible to design the RAS so that someone who does not meet FACS criteria may still be entitled to receive support via prevention funding, and could therefore still receive an individual budget – an important consideration given the current emphasis upon preventive strategies for health and social care.

5.40 Some of the evidence submitted to us suggested this could be a way forward. Gateshead Borough Council told us:

“Individual budgets will encourage the use of self-assessment to allocate resources. The ILF will have to review how it carries out its assessments in the light of this development. A single national self-assessment tool should be developed that applies to all agencies including the ILF.”

Similarly, the Disability Alliance remarked that:

“Applying a national standard of financial support for care services based on local assessments appears to be the fairest method of ensuring a more-or-less universal regime of entitlement to ILF, at least in the next few years.”

5.41 In evidence to this review, In Control has argued that “full integration means one funding stream, one RAS, one assessment, one charge, one system of monitoring and accountability.” We agree that this is the sort of system that will best serve users, but it is one that places very big question marks over the ILF in its current format, and in particular this would not be suited to the Trust Deed structure. **We recommend that the Government prepares the ground for the eventuality of a national RAS to ensure that findings from the IB pilots can be acted upon quickly. The policy significance of a national RAS is such that this work should be led by the two key Government departments – DWP and the Department of Health. Clear implications for both local authorities and the ILF need to emerge from this study.**

Summary

- 5.42 This section of the review has identified self-determination as a key element of the Government's new strategy on disability. It has considered self-determination conceptually and in practical terms, focusing particularly upon ideas around life planning, user-led support systems, self-assessment and resource allocation systems. In general we have found that the ILF does not measure up well to the tenets of self-determined care. We have concluded that these developments are likely to be essential elements in strategy and practice over the next few years, each of them carrying enormous implications for the current modus operandi of the ILF. We have recommended that steps be taken to prepare for such eventualities by undertaking a series of reviews of policy and practice so that any subsequent change is effectively addressed.

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Section 6: Operational Framework: Flexibility

Introduction

- 6.1 One of the prime motivations for people who take up cash for care opportunities is the chance to exercise choice and control over the way in which they use their funding, and to do so in ways that make most sense to their lives, with minimal interference from outside. The new policy emphasis of the Green and White social care documents^{1 2} also puts a premium on programmes that can be delivered flexibly and with the maximum degree of discretion for the service user. However, such flexibility is not absolute, and there are various constraints which in practice will limit this ambition. In the case of the ILFs there is an inherent tension between balancing the desire for optimum flexibility with the requirements of accountability.
- 6.2 The ILF is a cash-limited budget managed by a Board of Trustees who have a prime responsibility to exercise their discretion to ensure the fund is kept within budget and that expenditure complies with the legal requirements of the Trust Deeds and conditions of grant agreement. We will examine the legal framework in greater detail in Section 10. In this section, however, we will explore the major tensions which arise in seeking to balance flexibility and accountability, and how this impacts on the lives of service users.
- 6.3 The discretion of Trustees could serve to make the ILF highly flexible and responsive to individual need. However, as we have demonstrated in Section 3, it is evident that the existence of discretion means there is an inherent tendency towards inconsistency. This observation embodies an essential tension within the ILF; while the organisation exists to provide financial support to promote independence to people with severe disabilities, its capacity to respond flexibly to individual needs is constrained by a legal framework, and while Trustees have some powers of discretion, how and when they choose to exercise such powers appears arbitrary. Far from providing flexibility of response, what this can amount to is simply inconsistent and unpredictable practice. Other respondents also emphasised their concerns that discretionary powers simply mean inconsistent practice and lack of clarity for service users (“discretion in individual cases often depends on the mood that day and is not fairly applied.”). We will address the implications of discretionary powers later in this section.

ILF Audit Trails

- 6.4 One of the ways in which flexibility may be constrained is in the demands which are made of service users in accounting for their expenditure. This is not something that is unique to the ILF; indeed, all cash for care models face a similar balancing exercise which they manage with lesser or greater success.

The ILF requirements for an audit trail are generally accepted by ILF recipients with some equanimity, as this letter from a respondent illustrates:

“Reviews can be a nuisance, as can insistence on authentication of expenditure, but both are very necessary and a part of the ILF’s job. Fine.”

- 6.5 As we reported in our overview of the consultation events, ILF users generally found the monitoring requirements in accounting for ILF expenditure easier to manage and less demanding than those associated with Direct Payments. The observation that: “You are not cross-questioned by the ILF about how you spend the money” was typical of many such comments.
- 6.6 However, this was not the experience of everyone, and a minority of respondents told us about “bizarre” accounting procedures, a perception that ILF is concerned with the “detail of every half hour”, a belief that “compared to Direct Payments the record keeping is more stringent”, and “disabled people find the administrative requirements of ILF returns arduous and overly bureaucratic.”
- 6.7 The general tone of the evidence gathered by the review indicates that the auditing process required of ILF recipients is not too onerous. Records have to be kept and need to be viewed by the assessor at the 2 yearly review; ILF funds are paid directly into a bank or building society account and a special account is not necessary, although the ILF advises clients that “lots of people find that having a separate account just for their money from the ILF makes it easier to work out and see how much money they have.”³
- 6.8 For ILF users who also make use of Direct Payments, the issues of accounting and audit can be multiplied. While people certainly value having a separate allocation of money from the ILF, we were advised in a submission from the Foundation for People with Learning Disabilities that:
- “Some people would prefer to be able to combine different sources of funding into one ‘pot’, with one accounting system (...). Some people complain that their local authority requires them to hold separate accounts for money from different sources (so that audit trails can be followed) and this adds considerably to the administrative burden on them.”
- 6.9 We agree that it is undesirable for people to have to comply with more than one accounting process. In addition to the inconvenience and concern this can cause to service users, the requirements of accounting for different expenditure in this way can have a considerable deterrent effect on prospective ILF users. We understand the limitations currently imposed by the Trust structure on the ILFs and we hope the experience of the ILF in participating as one of the funding streams for the Individual Budgets pilots should be helpful in illuminating both the difficulties around duplication but also pointing towards some of the possible models of integration. **We recommend that the ILF should work with its IB partners and other local authorities and should build on the emerging lessons from the Individual Budgets pilots to agree a protocol for a shared accounting system which removes**

the need for individuals to be separately accountable for ILF and Direct Payments expenditure.

- 6.10 A significant minority of respondents (primarily those working in a local authority) raised concerns that the audit trail for ILF expenditure is insufficiently rigorous. For example:

“The current system whereby ILF review every 2 years and may ask to see bank accounts is most unsatisfactory. The funds come from the public purse and service users should be accountable for the spend.”

“Little monitoring, which can lead to financial abuses by unscrupulous carers.”

- 6.11 We recognise that there has to be proper accountability for the use of public funds, but we do not accept that this requires an administratively heavy system. The ‘light touch’ approach to audit followed by the ILF appears to be appropriate and proportionate, and is easily managed by most ILF users. There is little evidence of fraud, but there is a high level of concern within the organisation about misuse of money, as we shall see below. We do not believe this should lead to tighter accounting processes which would bring their own administrative and bureaucratic costs. The first phase evaluation of the In Control programme⁴ has arrived at a similar conclusion, noting little evidence of misuse of funds and observing a move to the ILF light touch model in the IC pilot sites.
- 6.12 It was argued in some submissions that one advantage of more frequent and rigorous monitoring can be that it allows the early detection of problems including where service users may be struggling to manage payments. In this light we welcome the recent decision of Trustees to develop a pilot to visit new applicants after 6 months to see how they are managing. **We recommend that the light touch approach to audit trails currently followed by the ILF should be maintained, but that greater attention should be paid to supporting and identifying service users who may have difficulties with the administrative process of managing the money.**

Restrictions on the flexible use of ILF

- 6.13 As our report on the consultation events makes clear, and as we have already highlighted, many ILF users emphasised the importance of the ILF in supporting and enhancing their daily lives. This was also a strong theme in the written evidence submitted to the review. In particular, it was pointed out that the ILF enables people to ‘live a life’, rather than merely to survive. At the same time, however, it was clear that restrictions on what ILF funding can be used for limits the flexibility that people require and effectively constrains the choices they are able to make. This was one of the most consistent complaints to emerge across all of our streams of evidence. These restrictions were identified across a number of domains including:

- Limitations of funding to cover personal care and domestic assistance.
- Failure to allow for on-costs associated with employing care staff and PAs.
- Lack of allowance for contingency money or roll-over.
- Difficulties caused by payment of funds in arrears.
- Cessation of funding upon admission to hospital.
- Restrictions on who can be paid for the care they provide.

Personal Care and Domestic Assistance (PCDA)

- 6.14 When the ILF was first established in 1988 it might be argued that the general understanding about the nature of social care was largely formulated in terms of people's needs for help with activities of daily living. In the years since, there has been a considerable shift in this understanding and increasingly the support needs of people with disabilities are conceptualised much more broadly in terms of support for people to participate in their local communities, fulfil their family responsibilities, be economically independent and to engage as citizens.⁵ The change in emphasis is therefore a shift towards looking at outcomes rather than focusing merely on processes, with PCDA in particular viewed as means to an end rather than ends in themselves.
- 6.15 The inflexibility of the ILF is rooted in the focus upon 'objective costing' (which leads to the preoccupation with inputs rather than outcomes) and the requirement for support to be 'ongoing' and linked to specified hours of support. In the recent DWP/ILF review of IBs⁶, for example, the response to a request to use ILF for Sky TV or horse riding lessons is that:
- "It is objectively ascertainable what an individual's need for personal care and domestic assistance is (but) it is unclear how it would be ascertained what their wider financial need for other support, for example for education and leisure activities, might be."
- 6.16 We do not think this is a helpful contribution to the quest for personalised welfare and individualised budgets, and reveals a limited understanding of the need for outcome-based flexibility in the future cash for care agenda. Of central importance here is the need to encourage people to see themselves as the central author of their own plans, rather than hiding behind a dubious distinction between 'objective' and 'subjective' costing bases.
- 6.17 Many of our respondents queried whether the current structure and limitations of the ILF are able to address these new requirements, for example, Barking and Dagenham identified this issue for the ILF, particularly in relation to its role within Individual Budgets pilots:

“ILF will need to begin to look at outcomes rather than concentrate on what the money should be spent on, as individuals will need to be given the freedom to choose when and how they spend their budget.”

- 6.18 This view was echoed by a number of respondents. Middlesbrough Council observed:

“The restrictions on the use of ILF payments appears to be inconsistent with the increasing move towards flexibility and user choice as demonstrated by In Control/Individual Budgets initiatives.”

And again, in identifying changes in the way ILF should operate, Derby City Council stated: “Expanding the range of allowable expenditure to reflect outcome based responses to needs instead of a rigid limit to the cost of staff support.”

- 6.19 The evidence we received from ILF users was often contradictory about the flexibility of ILF payments in supporting social participation. While some people told us that the ILF enables them to participate in society, far more ILF users shared their frustrations in not being able to use the ILF for support – for example – with leisure activities. It was remarked that the ILF merely “covers the bare bones” of support needs, and that it compared less favourably with Direct Payments which many people experience as more flexible.
- 6.20 As ILF recipients told us at all of our consultation events, not only is participation in certain leisure opportunities ruled out of ILF support, but even where ILF will pay for the support needs of a person in certain activities, it will not fund the costs for a PA to also participate in such activities. This means that if a person wishes to undertake certain activities (for example, going horse riding, or swimming or to the cinema) they will have to meet the costs of their PA also taking part out of their own pocket. Similar constraints apply to holidays, and while the ILF will pay for the support needs of a person while they are on holiday, the costs of taking their PA with them have to be met by the person themselves.
- 6.21 Not surprisingly, the limitations of the designation of ILF support for PCDA only has arisen as an issue in the Individual Budgets pilots where there is a desire for greater flexibility in the use of funds. The ILF has argued (correctly) that at present their Trust Deeds require them to ensure that payment is made only for personal and domestic care. However, this is sometimes perceived by partners, and by service users, simply as an ‘excuse’ for the ILF’s unwillingness to consider more flexible support. What ILF money can and cannot be spent on also raises issues about the boundary between health and social care. In the course of the review we heard repeatedly from witnesses about the potential benefits to a service user participating in one of the Individual Budgets pilots who had used some of their IB money to fund the installation of air conditioning within their home:

“For instance, if you look at some of the innovative things that people are using Individual Budgets for; there is one lady I know of (...) who has used some of her individual budget to have air conditioning installed in one of the

rooms of her house because she has respiratory difficulties, particularly if it is hot and humid conditions, and so being able to have air conditioning actually makes a huge difference to her life. Well, something like that wouldn't be allowable under the ILF! Or I can't imagine that it would be!"

6.22 This illustration also raises the inflexibility that arises from the ILF presumption that care will be provided via ongoing support by a PA or agencies. As Leicester City Council pointed out to us in written evidence, in some cases independence may be promoted or longer-term needs reduced if one-off items are purchased. This may include telecare, telemedicine and communication aids such as computers adapted to meet individuals' needs.

6.23 A view that was frequently expressed in written submissions is that the ILF has become "increasingly anachronistic." Many submissions acknowledged the important contribution that the ILF has played but emphasised that it is out of step with the overall direction of individualised care. The following comments underline this point:

"The ILF is an outdated model which is past its sell-by date."

"existing funding mechanisms are outdated and unsatisfactory."

"(ILF) policy and procedures are now out of line with local authorities across the country, and the time has probably come for either an overhaul or disbandment of the Fund."

6.24 We agree that the restrictions on ILF being allocated solely to support PCDA is out of step with the desired direction of support for independent living. We accept that the Board of Trustees is currently constrained by the terms of the Trust Deed, and we will return to these issues in Section 10. **We recommend that the limitations on the use of ILF funding for personal care and domestic assistance must be revised and updated to take full account of the wider objectives of supporting independent living, such as supporting leisure opportunities and participation in the community.**

Costs of employing care staff

6.25 A widely reported shortcoming of ILF costings is the failure to allow for the various on-costs associated with becoming an employer of care staff and Personal Assistants (PAs). We have previously discussed the difficulties of ILF payments not matching those made by local authorities, and the problems in rates of pay for care staff, but this is a different matter which has a number of dimensions.

6.26 In the consultation meetings with ILF users it was suggested that 'start up' money would be especially helpful in enabling people to become ILF users and to recruit and employ care staff. This was also a theme that was repeated in written submissions to the review. A start up grant would cover the costs of advertising for PAs, writing job descriptions and organising training. It is possible for claims to be made to the ILF for the reimbursement of these

costs, but this still requires people to have to find the money themselves in the first instance. Many respondents highlighted the inadequacy of the ILF payments in failing to allow for the full costs of employment, for example:

“I was not able to work out how the hours agreed had been funded – where was the annual leave allowance, the training allowance and sickness allowance?”

- 6.27 The failure of the ILF to allow for recruitment and ongoing employment support costs is in contrast to the arrangements for Direct Payments. This can mean that people who receive both DPs and the ILF can benefit from a local authority-funded support service to manage employment related costs, but for ILF recipients who do not also receive DPs, this support is absent, as this submission from Dundee City Council indicates:

“ILF only pay minimum statutory costs whereas Direct Payments ensures greater flexibility for users by paying employer on-costs. Local authorities provide much greater support and monitoring at a local level which can ensure any issues or difficulties for users e.g. in managing a direct payment or with employing staff are dealt with quickly.”

- 6.28 Leicester City Council argued that the lack of an allowance for employer costs within ILF funding also represents a shunting of costs to the local authority in many instances. However, such costs do not count as part of the local authority £200 contribution (unless that element can be specifically identified which is often not possible). Clearly, it is a matter of chance whether or not people using the ILF receive support with the costs and responsibilities of being an employer.

- 6.29 Many respondents remarked that the lack of support with on-costs means that there is inadequate recognition of the costs of being a good employer. As the Leonard Cheshire Foundation observed:

“Disabled people find the financial limit of the ILF increasingly insufficient to enable them to purchase adequate support and be good employers. The cost of wages of staff and agencies increase and there are extra costs such as training and pensions which disabled people would wish to provide.”

- 6.30 These extra costs could include sickness and holiday absence, but also redundancy payments for PAs if their employer dies, and retainer arrangements for funding being discontinued if a service user enters hospital. If ILF users are not told about their statutory employer responsibilities there can be, as the Penderels Trust argued in evidence to the review, a “greater tendency for cash in hand payments with the ILF than with the more regulated Direct Payments”, with all the attendant risks both for users and employees. Cheshire County Council suggested to us that current practice in enabling service users to meet their liabilities as employers is “haphazard” and therefore “puts service users at risk of challenge under Employment legislation.”

- 6.31 For ILF users the lack of support with becoming an employer can leave them having to find their own way through the complex rules and risks associated with hiring care staff (including compliance with employment law, payroll management, and health and safety regulations). We do not underestimate the challenges which becoming an employer of PAs can represent. As we observed in our report on the consultation meetings, many ILF users told us how difficult they had found it (particularly at the beginning), and the problems they had in understanding what they had to do. Managing issues around pay roll and associated tasks can be daunting and many service users pointed out that they are – in effect – running a small business, but without the benefit of practical support or preferential tax arrangements, as this comment illustrates:

“The only point of criticism I have is that due to tax, national insurance, wage packets and payment records etc our son and carers have the same accounting and paperwork as a company.”

- 6.32 In the face of such challenges it is not surprising that many people find the responsibilities of becoming an employer too much to manage. Some choose to employ a support agency to deal with the employer responsibilities on their behalf. An allowance of £10 per week (£12 from October 2006) is available from the ILF to pay for the costs of ‘book keeping’. Worcestershire social services remarked to us that there may be particular issues where the ILF recipient has learning disabilities and their family is responsible for their care, in such circumstances employing a book keeper can be especially attractive:

“The introduction of a book keeper/administration person can remove a lot of the worry. A book keeper is often used to run the whole ILF package (especially where the parents are elderly), including sorting out a rota for the carers and issues around expenses. This needs to be paid at more than £10 per week.”

- 6.33 Some respondents who sent written evidence to the review told us about their experiences in not knowing how to go about getting support in dealing with employment issues with the consequence that they had often incurred significant additional costs, for example:

“It would be a great help if ILF could furnish us with a simple contract of employment to save worrying about this necessity and having to pay hundreds of pounds for a solicitor.”

- 6.34 We agree with the weight of the evidence submitted to the review that ILF recipients should be adequately supported in their responsibilities as employers. The written submission to the review from the ILF Board of Trustees acknowledges that “our system assumes rather too readily that funding alone empowers people” and recognises “that simply transferring responsibility to vulnerable people without adequate support can create new stresses.” The ILF submission also identified the decision of Trustees to pay automatically (rather than on demand) statutory employer-related costs; funding to support this development was approved by Trustees in December 2006. We support this fully. **We recommend that the ILF should, as a matter of policy, recognise the additional on-costs associated with**

employing PAs, we further recommend that the ILF should fully fund the support needed by ILF recipients to manage their responsibilities as employers, and that it should be recognised that this is not simply about recompense for ‘book keeping’. We would also urge the ILF to examine the possibility of paying an extra start up grant to new users in recognition of the costs incurred in initial recruitment processes, and paying for appropriate advice which the ILFs are not in a position to provide directly.

Contingency costs and roll-over

- 6.35 Under-spending on ILF payments cannot be rolled over, other than on a very limited scale. Payments are made on a four weekly basis for recurring needs that have been identified and costed, and the amount allocated is to be used within this period. Evidence to the review identified the shortcomings with this rule. It is out of step with the approach of Direct Payments (where roll-over is possible), and it fails to allow sufficiently for fluctuating chronic conditions and mental health needs. Roll-over would allow people to accumulate a contingency fund which could allow a more flexible response to circumstances as they arise and which “can make the difference between a package succeeding or failing”, as this person acting as an appointee for a relative remarked:

“The best change would be to allow the client to have rollover of funds. This would be of paramount importance when you hit a care problem. You would be able to deal with this immediately. At the moment you must contact ILF. This is time consuming. You are stressed and it does not make for easy problem solving.”

- 6.36 This issue was also identified in the consultation meetings. We also note that this matter had been discussed within the ILF user group where some users had reported being told that accumulating monies “constituted a misuse of ILF funding.” The lack of flexibility in responding to changing support needs takes no account of individual circumstances. We were told, for example of a person who needs care when her husband is away on shift work, and it was remarked:

“ILF would not fund such a client because the shifts that need covering with personal care and support do not fit into a 4 week cycle. This is against independent living.”

- 6.37 In some circumstances we were also told that money builds up not because needs fluctuate, but because there are insufficient services available. This can be a particular issue for people with very complex and specialised needs where “money cannot be spent when there are no specialised services to purchase.”

- 6.38 **We recommend that more flexibility should be allowed on the roll-over of funds in recognition of the fluctuating nature of people’s needs, and the**

beneficial effects of being able to establish a small contingency fund. At the very least, we recommend that arrangements for the ILF should match those employed in Direct Payments.

Payment in arrears

- 6.39 ILF payments are made in arrears every four weeks. The inconvenience and impracticality of this arrangement was repeatedly identified in evidence to the review, as was the argument for replacing this with payment in advance. This is the approach that is followed with Direct Payments, and to have a different payment basis operating for the ILF seems confusing and potentially highly inconvenient for ILF recipients, making the management of bills extremely difficult and calculations unnecessarily complex. Indeed, as an ILF user remarked in a written submission to the review, this is more than inconvenient and it effectively places recipients in a very difficult position as employers:

“..until you become established it is impossible to comply with employment law and pay your staff wages on time. This is also a problem if you use an agency because you are always in arrears with your payments to them. This creates real difficulties for newly funded disabled people who do not have any spare money to fill this gap.”

- 6.40 This observation was reinforced in the feedback in our user consultation events, where we report of payment in arrears:

“this can cause hardship in the start-up phase of using the ILF ... Many people commented on the need to ‘double fund’ arrangements whenever they took on a new care worker or PA since there would need to be a transitional arrangement where they shadowed current staff and were trained.”

- 6.41 The requirement of the 2006 Deed for the ILFs to make payments on the basis of accrued liability is out of step with common local authority practice of payment in advance for Direct Payments, and the lack of consistency and increased complexity this presents ILF users cannot be justified. **We recommend that the ILF should move to a system of payments four weekly in advance, instead of in arrears, at the earliest opportunity. This would not replace the recommendation that there should also be adequate allowance for the start-up costs of initiating an ILF care package.**
- 6.42 A similar situation arises in respect of the reluctance of the ILF to backdate an award from the date of the application. As Middlesbrough Council pointed out in written evidence this can cause both personal and financial hardship to users, and may lead to a loss of identified carers and the jeopardisation of tenancies. Backdating is only considered on request (even in the case of acknowledged ILF error). It is important that applicants are not disadvantaged by any delays or errors arising from the ILF application process. DLA is awarded from the date of the request for the claim form as long as it is returned properly completed within six weeks. A similar arrangement for ILF is

not unreasonable and **we recommend that ILF be payable from the date that a properly completed application form is received.**

ILF payments and hospitalisation

- 6.43 We were told about the problems which can arise when an ILF recipient has to be admitted to hospital. For people with multiple and complex needs this can be a frequent occurrence. The rules on ILF payments differ for people who use care agencies or self-employed PAs, and for those who are direct employers. In the case of the former, ILF payments are suspended from the day after a person goes into hospital. For people who employ PAs privately, ILF payments are not affected for up to 7 days. If an admission is longer than 7 days a request can be made for a retainer payment that will be paid for a further 21 days to enable ILF users to continue paying their PAs so that they have some job security while the person is in hospital. If people are in hospital for more than 4 weeks, ILF payments are stopped entirely but will be restarted upon discharge.
- 6.44 When a person is admitted to hospital DLA funding ceases in order to avoid duplication of public funding; because of the linkage of DLA and ILF this also means that ILF support ceases. Implicitly it is assumed that a person's entire care costs are – for the time being at least – being met by the NHS. However, this is not necessarily the case, and we were told of the importance of being able to continue to use PAs to support people even during their hospital admission. We recognise that PAs acquire an expertise and detailed knowledge of the particular needs of those they assist with independent living, and they may be the people who are best placed to meet those needs regardless of where the person is accommodated. This is likely to be the case, for example, with people who have extreme communication difficulties that their PAs are skilled in understanding, or where a person has significant learning disabilities. Hospitals are busy places where nursing staff rarely have time to fully understand the individual needs of patients, and the opportunity for PAs to provide appropriate support could be invaluable.
- 6.45 **We recommend that the DWP and ILF should adopt a more flexible position in respect of hospital admissions. If an ILF user (or their family or advocate) can make the case for their needs during a period of hospitalisation continuing to be met by their PA, we recommend that the ILF should support such requests wherever possible. Equally, while we accept that ILF support cannot continue for an indefinite period of hospitalisation, the four week cut-off seems arbitrary and we recommend that this should also be applied with more flexibility.** We acknowledge that this recommendation implies de-coupling ILF from both DLA and FACs and that the 2006 Trust Deed does offer more flexibility around payments during hospitalisation than has been the case to-date.

Restrictions on who can be paid

- 6.46 Finally in this section we consider the restrictions on who can be paid to provide support under the rules of ILF funding. We received many representations concerning the rules against allowing relatives within the same household to be paid as PAs (although this rule does not apply to relatives living in other households). Many of those who raised this issue with us failed to understand why this prohibition should exist. From their viewpoint the rule appears exploitative and unfair, as these comments illustrate:

“..when I cover for absent staff for my adult (and financially independent) daughter, I am obliged to forego paid work and undertake demanding work unpaid.”

“I cannot for the life of me see why you will not reward a relative who lives in the same house as the claimant. After all, somebody has to care for them. In fact in my case there is never going to be enough money in the benefits system to pay for full time care for my son. It is inevitable that my wife and myself will have to provide some of the care for him.”

- 6.47 In our consultation meetings we found a range of views on this matter, but many people argued that since relatives would always provide care when there was a need for it, it was morally wrong that they should not be paid for their input (particularly when the opportunity costs of their care were considered). In written evidence to us the Hampshire Centre for Independent Living puts the issue within the framework of choice, stating that: ‘As long as the service user is in control of the payments then he/she should be at liberty to employ whoever they choose’.
- 6.48 We recognise the sense of injustice which many ILF recipients and their families feel in not being allowed to make payments to co-resident relatives, and we have not found this to be an easy issue to address. However, we also recognise the real dangers which could arise if this was permitted. If payments can be made to relatives, the nature of their relationship with the person they are caring for can be profoundly changed – as one respondent said to us “when you pay your relatives, they will never do what you want them to do if they don’t agree with it” People in need of support and care can easily find themselves locked into a situation whereby their ILF payments and other benefits become a central element of household income, and in such circumstances the opportunity to exercise genuine choice and control can be compromised. This can be a particular issue with people with learning disabilities, but it can arise in any care situation.
- 6.49 In our report on the consultation events feedback we noted that people valued the fact that using the ILF meant that they did not have to rely so heavily on family (and friends) for help because they were able to pay care workers and personal assistants to help them. From the point of view of family members and carers, knowing that a person was getting support or being able to get out and about to do what they wanted, also provided reassurance. It also relieved them of some pressure, and while most family members want to be involved in

supporting others, many recognised that being able to delegate some of the responsibility made a big difference to their own lives.

- 6.50 **We recommend that the ILF should, in general, retain its current policy of not allowing payments to be made to relatives living within the same household. However, the Trust Deeds do allow the Trustees to exercise discretion in this matter, and we recommend that this discretion continues to be exercised in exceptional cases.**

Summary

- 6.51 In this section we have addressed a number of dimensions along which the flexibility of the ILF could be much improved. We have examined the tensions which inevitably arise when an organisation is bound by a set of rules but nonetheless has powers of discretion. The resulting uncertainty and inconsistency which this can introduce is highly regrettable from the perspectives of service users and their advocates. Despite the opportunities which the ILF has to exercise discretion, it has tended to operate in a relatively inflexible manner. We have made several recommendations which would improve the flexibility and responsiveness of the ILF if adopted. These have been principally concerned with the ways in which ILF money can be used, and many of the recommendations address the overall coherence of ILF with the parallel system of Direct Payments, while also ensuring that the ILF is fit for purpose and is able to address the changing world within which it is now located.
- 6.52 In written evidence to the review, In Control succinctly identifies the importance of flexibility:
- “One of the great advantages of a system of personalised budgets is that it removes the rationale for tightly constraining how people use their money. If people are given a certain level of funding, then they can determine how best to use it. The current ILF rules are not designed in that spirit and offer only limited flexibility, and can even create perverse incentives for local authorities to offer more institutional services.”
- 6.53 We fully agree with these sentiments, and they stand in sharp contrast to a recent issues log in response to the IB pilots⁷ in which it is suggested that a video/DVD be produced for people who get IBs to help them understand the limits and use of the respective IB income streams. This is taking us down completely the wrong path. If the IB partners are to play a role in supporting and promoting the development of independent living, it is time to sweep away the anachronistic rules which conceptualise support for people to live their lives purely in terms of care.

References: Section 6

¹ Department of Health (2005), *Independence, Wellbeing and Choice: Our vision for the future of social care for adults in England*, Cm 6499, London: The Stationery Office.

² Department of Health (2006), *Our Health, Our Care, Our Say: A new direction for community services*, Cm 6737, London: The Stationery Office.

³ Independent Living Funds (2006), *Getting Your Money*, Leaflet 6.

⁴ Poll C., Duffy S., Hatton C., Routledge M (2006), *A report on In Control's first phase 2003-2005*, London: In Control.

⁵ Office for Disability Issues (2006) *Improving the Life Chances of Disabled People: The first annual report from the Office for Disability Issues 2006*, para 143.

⁶ Department for Work and Pensions (2006), *The Issues Log: the ILFs within the Individual Budget Pilots*.

⁷ Ibid.

Section 7: Operational Framework: Values and Outcomes

7.1 Reference has briefly been made in Section 1 to the significance of changing ideologies of disability in shaping policy and practice, and we have been explicit in the way in which we have used a framework of appropriate values to assess the ILFs. In this final section of our examination of the operational framework of the ILFs we return to the importance of the ways in which disability is conceptualised and understood. It is evident that this is an area that has changed enormously in the recent past, with a paradigm shift taking place over the past thirty years or so in the nature of the dominant discourse of disability, followed by a parallel shift in policy aspirations since at least the Improving Life Chances report.¹ Our purpose in this section is to consider the extent to which the ILF has engaged with these changing conceptualisations and in doing so to assess whether it is well placed to take forward the new policy and practice agenda.

Changing Ideologies of Disability

- 7.2 There can be no doubt that over the past thirty years or so our understanding of impairment, disability and the complex process of disablement has been radically changed, with traditional individualistic medical explanations challenged by a more socio-political understanding. Much of this challenge has centred on the notions of ‘citizenship’, participation and empowerment, and it is this conceptualisation that has led to the growing interest in ‘cash for care’ programmes. One of the clearest expositions of the concept of citizenship and impairment has come from Morris² who identifies three key dimensions:
- 7.3 **Self-Determination:** Self-determination is about making personal choices, and it has become necessary to argue not only for the removal of barriers to self-determination, but also for the provision of assistance which makes self-determination possible – a point we make strongly in Section 5 on Self-Determination. For Morris, this concern echoes the concept of ‘autonomy’ in the citizenship literature – the ability to determine the conditions of one’s life and to pursue one’s life projects. As we have already noted in Section 1, she identifies three crucial messages that are relevant to the citizenship of disabled people. First, a need for support to make choices does not mean that someone cannot experience self-determination. Secondly, in order for disabled people to have equal opportunities to be full citizens it is necessary to take action to remove barriers to self-determination and, for some disabled people, it will be necessary to use resources to support self-determination. And finally the action to be taken must be determined by disabled people themselves. This last point is critical and we will return at a later stage in this report to the ways in which the ILF engages with those who use its services.
- 7.4 **Participation:** A common theme for disabled people and their organisations has been the promotion of the right to be included in mainstream society and

to participate in family, community and national life. Participation therefore requires and gives expression to self-determination, and is seen as an integral part of being a citizen. However, support for activities that would promote community participation is not generally covered in community care assessments which are increasingly targeted on a limited range of activities focused on keeping people from risk of physical harm.

- 7.5 **Contribution:** Disabled people have emphasised the value of their contribution to economic and social life as volunteers, parents and family and community members, but they are often assumed to be unable to take on such responsibilities. Morris points to an assumption that once someone needs support to go about their daily lives, they are typically seen as passive recipients of care, other than through a financial contribution towards the cost of their support. This, she argues, is a double-edged sword: charging policies reduce people to the income level which is considered to be just sufficient to live on and which makes community participation difficult; and at the same time people are not expected or helped to make any other contribution to their family, community or society.
- 7.6 This very brief examination of 'ideologies of disability' constitutes an important part of our review of the ILFs because all social policies are value based, and it is vital that there is clarity about these underpinning values and the extent to which policies, services and support are consistent with stated values

Outcome Based Approaches

- 7.7 'Outcomes' refer to the effects or impacts of interventions on the welfare of service users and should be distinguished from outputs, which are, strictly speaking, service products. Ultimately an outcome can be defined in strictly subjective terms as the extent to which an individual feels his or her needs have been met. In recent years social policy has moved decisively in the direction of articulating an outcome based approach.³ The 1998 White Paper on social services identified the core goal of promoting independence in adult social care, and providing the support needed by people "to make most use of their own capacity and potential."⁴ Subsequent policy documents provided further elaboration of the desired outcomes of service support -notably in the various National Service Frameworks and Strategies, and most evidently in the Every Child Matters reforms of children's services, and in the corresponding community services White Paper for adults, Our Health, Our Care, Our Say which confirmed the importance of 7 central outcomes:
- Improved health and emotional well-being.
 - Improved quality of life.
 - Making a positive contribution.
 - Choice and control.

- Freedom from discrimination.
- Economic well-being, and
- Personal dignity.⁵

7.8 This is an important change in policy conceptualisation that has been shaped by, and in turn shapes, the more specific issue of independent living for people with disabilities. ODI, for example, is committed to developing an overarching set of outcome-based indicators to measure progress towards the goal of achieving substantive equality for disabled people by 2025. This will build on indicators and targets already in place, but it is acknowledged that there is much more to be done to capture the many different aspects of people’s lives that are affected by disability. Issues that need to be addressed include:

- What outcomes should be chosen for measurement and reporting?
- How to distinguish outcomes for disabled people from outcomes for the non-disabled population – there is no single ‘gold standard’ measure of disability and it may therefore be necessary to use different definitions of disability for different outcomes.
- How to ensure that data are available to measure progress on chosen outcomes. Existing data sources will not support all potential indicators, and work is being taken forward to explore the development of new data sources.

7.9 A useful contribution to this debate has been made by Duffy⁶ who identifies six ‘keys to citizenship’, and in so doing links the debate on ‘ideologies of disability’ more closely to its policy implications:

SIX KEYS TO CITIZENSHIP	
Self-determination	The ability to control your own fate and make decisions for yourself.
Direction	A unique sense of purpose by which to identify your role within your community.
Money	The means to independently meet your needs without being dependent on others.
Home	A place of your own in the community where you are seen to belong.
Support	Being able to offer others the chance to help and be useful to you.
Community life	To make a contribution to the community by your meaningful presence and participation.

The Role and Response of the ILF

- 7.10 The ideas and language of the social model of disability pose a major challenge to the traditional organisation and procedures of the ILF. Given that the ILF originated at a time when the dominant discourse tended to be a medical rather than a social model of disability, it is important to attempt to discern whether and how the ILF has itself evolved ideologically. The ILF itself concedes that it “starts from a set of policies set in a different climate with different objectives,”⁷ but in submitting evidence to this review stated that:

“The ILF approach of putting resources plus support rather than prescriptive services into the hands of disabled people is in line with the social model and supports the new Disability Strategy set out in the SU report through advancing the aspirations of the independent living movement.”

- 7.11 In considering the extent to which this is indeed the case we have been able to draw upon two kinds of evidence – that available in ILF documentation and that gathered from other sources as part of our review.

ILF Policies and Plans

- 7.12 The ILF appears to be aware of the new context and the changes in approach that might be expected to flow from it. The 2005/6 Business Plan, for example, suggests that the Strategy Unit report “creates an opportunity for the ILF to work in partnership with other organisations in a very constructive way,”⁸ whilst the 2006/9 Strategic Plan⁹ states that ‘The ILFs recognise the need to be outward looking, staying in touch with ‘bigger picture’ issues’ [p7]. More pointedly, there is an acknowledgement that the ILFs must change:

“There are challenges to develop very different models in the future; it will not be enough for the ILF to keep doing the same things well [p11]...The ILF now needs to ask different questions. It is not sufficient to ask ‘Is the service of good quality?’ Other questions now are ‘Is it the right kind of service?’ and ‘Is it what people really want?’ [p12]

- 7.13 Of particular significance here is the recognition of the need to look beyond procedural issues towards user outcomes:

“We recognised the need to evaluate what is the contribution we make to the wider issue of independent living. For example, we need to assess what level of opportunity we create for the development of incentives for a person to take choice and control over how they live the life they would like to have as a disabled person.” [p13]

- 7.14 The ILF Annual Report for 2004/5 identifies the purpose of the ILFs as follows:

“to provide financial assistance under the terms of the Trust Deeds in an efficient, cost-effective way that respects and supports a disabled person’s

requirements for personal care and domestic assistance which enables independent living.” [p3]

- 7.15 As it stands this mission statement is somewhat process driven, but the same report goes on to acknowledge the importance of a more outcomes based approach:

“Process redesign will go hand in hand with the continued review and restatement of policy...It is important that the ILF measures its performance in terms of outcomes rather than activity.” [p19]

These outcomes are identified as needing to show that the ILFs are:

- effective in what they do;
- efficient in what they do;
- have or encourage a supportive relationship with disabled people;
- make a positive contribution to independent living;
- build on successes achieved to date.

- 7.16 More recently the Strategic Plan for 2006/9 outlined the User Service Framework – the CHOICE model – consisting of:

- **comprehensive:** every ILF applicant/user has available to them the information they need to access, receive and manage payments from the ILF;
- **highly professional:** the ILF will ensure that the right working environment exists within which all staff have the necessary skills, knowledge and resources to deliver business requirements;
- **open:** the ILF will be accessible to all potential applicants/users, and any real or perceived barriers will be eliminated;
- **individual:** the rights of individual applicants/users will be respected, and the decisions made will be based on an understanding of the individual and collective needs of those involved with the organisation;
- **correct:** the amount of funding offered to users will be appropriate for their circumstances, accurately calculated, paid on time and used by them for the intended purpose;
- **effective:** ILF processes will be free of unnecessary bureaucracy and will be consistently operated, achieving high levels of efficiency.

- 7.17 The Strategic Plan does go on to state that there is recognition of the need to also evaluate what contribution the organisation makes to the wider issue of independent living, but no detail is given on what this means or what it would entail.

- 7.18 Overall, as far as we can judge, on the basis of the published documents available from the ILFs, there does not appear to be a strong link with the discourse of the disability community, the principles underpinning Improving the Life Chances of Disabled People or the outcome focused policies associated with the Every Child Matters reforms and Our Health, Our Care, Our Say. Although there is an awareness of the fast moving environment and an apparent willingness to engage with it, the focus tends to be upon process driven issues that demonstrate efficiency and effectiveness in the allocation of public monies – itself a right and proper consideration – rather than on user determined outcomes.

Views of Partners and Service Users

- 7.19 Strong and repeated views were put to us that the way in which the ILF conceptualises its role makes it difficult for it to engage with a new approach based upon self-determined care. Of prime importance to those taking this view is the argument that the ILF model is rooted in a professional determination of inputs rather than the accomplishment of user-determined outcomes. This is partly about the type of care, but also about the way this care is required to be ‘timetabled’, as these witnesses observed:

“They take a much more traditional view in terms of having to have a care worker perhaps or a social worker go around, and have someone provide what we would say is traditional personal care.”

“I do feel that some staff need to spend some time on the front line with disabled people to enable them to understand the difficulties that can be encountered on a day to day basis for people using the fund – especially in the case of those who have learning disabilities and present challenging behaviours – sometimes trying to explain to the caseworkers that it is in some cases impossible to pin down exact “timetabled” hours when care will be employed because of the difficulties the individual may have. Trying to quibble over an hour here and there that a person may or may not use in any given specific week if they do not feel compliant, can often lead to several letters back and forth and a lot of wasted time.”

- 7.20 Some respondents made the point that the way in which the ILF thinks about support for independent living is at odds with the nature and spirit of IBs:

“ILF support is based around the types of service people get, whereas individual budgets is about giving people the money and then helping them choose what they want. It’s not service driven; it’s not so many hours of care...I suspect it’s quite an old-fashioned model, quite paternalistic.”

- 7.21 Amongst the suggestions offered by Coventry City Council was one for the ILF “to work with users and potential users to develop a shared understanding of what is independence and what is quality of life.” What seems to lie behind this suggestion is the need for the ILF to engage more fully than hitherto with the agenda on outcomes. One respondent summed it up in this way:

“What we want to move to is an agreed set of outcomes about living independently at home, common outcomes that all of the agencies are signed up to. That’s the principle.”

7.22 This is a position adopted by others in evidence to us. Greater Peterborough Primary Care Partnership, for example, argues that: “the ILF needs to be more outcome based and allow more flexibility in individuals care packages to ensure outcomes are met as the future develops towards self-assessment and individualised budgets.” Similarly the London Borough of Brent calls for the ILF to be more closely tied to the outcomes laid out in Our Health, Our Care, Our Say.

7.23 Of course, in all of this it has to be remembered that the ILF is not entirely free to use its resources in any way that it chooses, and it has been noticeably hidebound by its Trust Deeds and Conditions of Grant Agreement – issues to which we will turn in due course. However, this section of the review is not about such legal restrictions but rather about whether the ILF has displayed a deep and rigorous understanding of, and commitment to, an aspiration based upon self-determined care. Some respondents felt it had failed to do so. In written evidence to us, In Control argues:

“It is simply not clear why the idea of a right to independent living should be distributed in such a narrow and artificial way to so few people. In fact it could be argued that the current definition of eligibility is based upon the medical model of disability, and that a broader model based upon citizenship would provide a better basis for distributing resources.”

7.24 Some respondents went further, and suggested that whilst the ILF appears to subscribe to the social model of disability and to self-determined care, it shows insufficient understanding of what this means for its own practice. One disabled person remarked:

“I’m not sure that people working at ILF really understand what independent living is. It’s weird that they are managing a key mechanism for delivering independent living and yet they don’t have the culture to go along with it.”

7.25 Another service user in receipt of ILF took a similar view:

“Times have moved on and this must be reflected in the review. It is clear that despite policy and procedural changes, the ILF is culturally behind the times. It assumes users are knowledgeable of independent living, and sees itself as an administrative body slightly outside current social care thinking.”

7.26 Underlying these and similar opinions was some degree of puzzlement that despite having pioneered cash for care programmes long before they became more fashionable in other quarters, the ILF had failed to champion or progress the independent living agenda; it had, in effect, marked time rather than become a catalyst for change:

“If anything changes it will take a long time to do so, and I think that there is a barrier to get over in terms of their general outlook on how you do this and

what independent living is, and what they exist for. I don't know that they see themselves as champions of independent living; I think that they consider themselves to be more of an organisation to distribute money to people to pay for other people to come in and wash them and change them almost and cook their meals. That's the sort of feeling I get"

"My perception is that the ILF, from having been by accident almost, at the forefront of developments, is now increasingly anachronistic."

Summary

- 7.27 In this section of the review we have considered the ways in which, and the extent to which, the ILF is well attuned with the modern discourse on disability and independent living. We have found that although the ILF has an awareness of the changing ideological and policy environment, it has failed to be a champion of, or catalyst for, such change. Rather it gives the impression of having been taken somewhat by surprise at these developments, and is now – belatedly – looking to join the party. This is a disappointing position for an organisation that was at the cutting edge of policy and practice in the late 1980s, and had the opportunity to be at the forefront of subsequent developments. All of this suggests to us that the ILF has yet to display a deep understanding and appreciation of progressive models of disability. It is difficult for us to make any specific recommendation in this respect; rather we take with us into the final stages of this review a concern that the ILF has not hitherto displayed the sort of ideological sophistication that we would have expected, and which we believe needs to be a pre-condition in an organisation that is promoting new models of independent living.

Operational and Strategic Frameworks

- 7.28 Sections 2 – 7 of the report have focused on various dimensions of the ILF's operational framework. We have looked in detail at how the ILF functions and have evaluated its operation against a template of six criteria, i.e: equity; transparency; accessibility; self-determination; flexibility; and values and outcomes. In each of these areas we have scrutinised ILF performance; identified any areas of good practice and made recommendations throughout for further improvement. Our analysis has covered a wide territory and drawn extensively on the body of evidence submitted to the review and gathered by our consultation processes. The operational framework has principally been concerned with how ILF users (and potential users) experience the ILF. This is the heart of the review, but it does not tell the whole story. We need also to consider how the ILF functions strategically, and how the strategic environment in turn structures the operation of the ILF on a day to day basis.

- 7.29 Sections 8 – 11 of the report turn therefore to address the strategic framework. We will address four main themes that have been highlighted in Cabinet Office guidelines for the review of NDPBs: strategic links and partnerships; openness and accountability; the legal framework; and corporate governance. Finally, in Section 12 we will draw together the overall findings, conclusions and recommendations from both the operational and strategic analysis.

References: Section 7

¹ Cabinet Office (2005), *Improving the Life Chances of Disabled People*, London. Prime Minister's Strategy Unit.

² Morris, J. (2005), *Citizenship and Disabled People*. London: Disability Rights Commission.

³ Henwood M and Waddington E (2002), *Messages and Findings from the Outcomes of Social Care for Adults (OSCA) Programme*, Nuffield Institute for Health/Department of Health.

⁴ Secretary of State for Health (1998), *Modernising Social Services: Promoting independence. Improving protection. Raising standards.* Cm 4169. London: The Stationery Office.

⁵ Secretary of State for Health (2006), *Our health, our care, our say: A new direction for community services*, Cm 6737, para 2.63.

⁶ Duffy, S. [2003], *Keys to Citizenship*. Liverpool. Paradigm.

⁷ Independent Living Fund [2006], *ILF Pilot Protocol, Version 1*. Nottingham.

⁸ Independent Living Fund [2005], *ILF Business Plan 2005/6. The Future Taking Shape*. Nottingham.

⁹ Independent Living Funds [2006], *Strategic Plan 2006-2009*. Nottingham.

Section 8: Strategic Framework: Links and Partnerships

8.1 Cabinet Office Guidance on the review of NDPBs states that this should include an examination of links the NDPB holds with relevant partners and programmes. This is particularly apposite in the case of the ILFs where throughout its history there has been a need to establish close and clear relationships with an expanding range of partners. This section of the review focuses upon the major partnering relationships of the ILF. We identify three key areas:

- The ILF-Local Authority Relationship
- ILF and Individual Budgets
- The Intersection with the NHS

The ILF-Local Authority Relationship

A Troubled Partnership?

8.2 The fates of the ILF and Local Authorities (LAs) have been inextricably bound together since the creation of the 1993 Fund which required an explicit partnership to be established, yet thirteen years on it remains an unsettled relationship. What is not in doubt, however, is that the prime responsibility for social care services currently lies with LAs – a point made strongly in the last Quinquennial Review: ¹

“In all aspects of the review it is to be borne in mind that since 1993 the primary responsibility for community care rests with LAs. The ILFs complement that provision but are not seen within wider Government policy as substituting for appropriate LA input.” [para 14]

8.3 This view, expressed in 2001, remains the case today, and it is important to remember that in terms of adult social care expenditure in England the total money allocated via the ILFs each year (approximately £220m) is very small in comparison with the LA annual budget for adult social care (£15 billion). The relationship did not get off to a good start in 1993 with suggestions that the Independent Living Transfer [ILT] – an initial three year additional funding source for LAs – was too often underspent, vired for other uses before the end of the year, or offset against overspent budgets, or a combination of these. Although separately identified for three years, the ILT was not ring-fenced, and suspicions were harboured that the money was often spent in an ad hoc way that had minimal impact on support for disabled people. ² This suspicion of the ways in which money can be ‘lost’ in the LA system continues to this day, and is a point that was repeatedly made to us throughout the course of the review.

- 8.4 The ways in which the ILF and LAs intersect (or fail to intersect) in respect of assessment and support for independent living for disabled people has been exhaustively examined throughout this report, especially in our analysis of operational procedures. We do not wish to repeat points that have already been established, but it is important at this stage to re-state that service users are often very unhappy with the lack of synchronicity between the two agencies. Indeed, the ILF itself concedes, in its Strategic Plan, that the two agencies have distinctive and non-aligned procedures:

“The background of the ILF originates within the benefits system, and whilst it acts as a top-up to local authority contributions, policy and practices are not closely aligned.” [p11] ³

- 8.5 The worry here is twofold. First that people will find it difficult to discover the ILF and traverse the application process, and secondly that they will find the existence of the two sources of support confusing and cumbersome - we have already reported much evidence to that effect.

The ILF and LA Responses

- 8.6 It would be wrong to imagine that the ILF-LA relationship has simply festered; indeed, both sides have made efforts to improve the situation. In the case of the ILF this has involved the creation of a LA Liaison Team [previously termed the Customer Services Team] that is currently developing a system of measuring LA performance in the context of the ILF. The intention is to target resources, identify areas where improvements can be made, discover where working practice conflicts and seek service improvements. This is very welcome, although attempts to improve the take-up of ILF in under-represented LAs is in tension with the recommendation of the Quinquennial Review against “any national or regional take-up campaigns.”
- 8.7 During 2006 the LA Liaison Team embarked on a series of pilot meetings with some LAs and planned a series of thirteen Regional Meetings. In written evidence to us a number of LAs expressed their appreciation of having a new named ILF link. This is a very helpful initiative by the ILF, although it is also disappointing that it has taken so long to get to this point. **We recommend that the ILF continues to develop customised links between ILF and LA staff.**
- 8.8 In some cases LAs have also been putting effort into developing a closer relationship with the ILF, most notably through the appointment of officers with a specific remit to liaise with the ILF and increase local take-up levels. Where this is the case then it seems that relationships can be less fraught than where individual social workers are simply left to their own devices in awareness of the ILF and supporting clients through an ILF claim. Nevertheless, LA contact officers can still find themselves in difficulty with ILF applicants. In written evidence to us, one officer said:

“I would like to see better business communication. I would like to see regular lists of applicants, recipients, offers, suspensions and stoppages sent to the LAs. This would allow me as a Contact Officer to know what was going on across the whole directorate...I do not have sole responsibility for ILF applications and do not know which social workers are making an application to the Funds or how well or badly they do this.”

- 8.9 These are important issues, for there is little point in both the ILF and LAs investing in a range of Contact Officers if best use is not made of them. However it is not only the ILF and LAs who need to be more joined up with each other in this respect, for within each LA there may also be a need to ensure the actions of individual social workers are coordinated with the remit of the LA Contact Officer. **We recommend that the ILF LA Liaison Team and the LA Contact Officers draw up a clear strategy (within the Data Protection Act) to demonstrate how maximum synergy can be achieved between the ILF and LAs, and that this includes issues of coordination within LAs between Contact Officers and individual social workers.**

ILF and Local Government: The Structured Relationship

- 8.10 The relationship between the ILF and LAs is not confined to operational matters; there is the much wider issue of whether there should be an integration of functions rather than merely an alignment of procedures. Perhaps the most distinguishing feature of the ILFs as compared with other cash for care programmes is the nationally determined nature of their arrangements. The ILF itself is in no doubt that this is a crucial advantage in the consideration of any future scenario, with other arrangements not seen as able to secure the requisite degree of consistency across every local authority in all parts of the UK.
- 8.11 The Quinquennial Review of 2001 did look at the possibility of transferring the ILF remit to local authorities but found “a significant proportion” of ILF clients strongly opposed to any such change. It noted that:
- “The principal arguments advanced were that local provision would be subject to local variations, changes in funding priorities and potential budget restrictions. The ILFs were seen as being more flexible and more readily available than Direct Payment schemes, and the existence of a programme operating a national scheme was considered a major benefit in comparison with differing provision between LAs.” [para 25]
- 8.12 However, the Review also noted a minority view that the LAs’ primary responsibility for community care should be acknowledged, and that the ILFs functions should be transferred to LAs, with the ring-fencing of the relevant funds being seen as a prerequisite of such a move. Although the Review remained unconvinced of the case for a transfer to local councils, it did concede that “the arguments for transferring the ILF function to LAs...may become stronger in the longer term.” [para 28].

- 8.13 One respondent summed up the overall dilemma in the following way, and in doing so captured one of the basic issues that this review has been set up to address:

“It’s no good simply making it (ILF) more flexible, without asking the question whose job is it to provide this money to disabled people? That’s the fundamental question isn’t it? We now seem to have two organisations that have a job of providing money for near identical purposes. How are we going to avoid a situation where two different agencies are transmitting money for the same purpose with different bureaucracies and different monitoring procedures? And that’s the fundamental political bullet that needs to be bitten in this debate.”

- 8.14 Five years on from the Quinquennial Review we have the opportunity to revisit this important issue. We have found opinion is still divided. On the one hand there are those who see the merging of the ILFs into local government as a rational solution, albeit with the need for some safeguarding of funds. The suggestion made by Leeds Social Services – “transfer of the resources available for ILF to local authorities and it’s ring-fencing to direct payments” – was echoed by others. On the other hand, we discovered opposition – often quite virulent – to any such proposal, with two main difficulties identified.

- 8.15 The first problem, and the one most often raised, is the belief that ring-fenced money would not be safe in the hands of financially hard-pressed local authorities. Indeed, this sort of observation was often made by people themselves working in the local government sector as well as by service users. In the view of one ILF user:

“Regulations on local authority social care funding are weak, and councillors increasingly deem the lives of disabled people as unimportant... therefore it is unwise to disband ILF and distribute the funds to each authority as it is unlikely to be used for the right purpose. However, if a larger review of social care funding took place then it is highly recommended that a single funding stream is implemented.”

- 8.16 In a similar vein, the Penderels Trust has said that: “If the ILF didn’t exist the worry is that the money would get dissipated into the larger local authority pot and would not directly benefit disabled people.” And in a strongly worded submission, Edinburgh City Council argues that ‘pressures on LA budgets are so powerful and compelling as to evade any financial discipline that might be attempted by ring fencing, however strongly entrenched.’ Warrington Borough Council similarly observed that:

“The fact that this care funding is held outside of the local authority means that it remains a reliable source as it is not at the mercy of the ebb and flow of differing and variable policy initiatives.”

- 8.17 Concerns such as these were also frequently expressed at the Consultation Events and in individual communications to us, and constitute a powerful body of opinion that is difficult to ignore.

- 8.18 A second problem is less political and more technical – that of determining how ILF monies might be allocated amongst LAs. In written evidence to the review, In Control point out that this would amount to somewhere in the region of £1.3m to each LA, but given the disparity in take-up across the country (an issue we have covered in Section 2 on Equity), if a budget transfer was based upon current uptake there would be clear winners and losers – an outcome that would equally apply to a funding transfer based upon population per area. In effect the very inequity of current ILF distribution itself becomes a factor that militates against change.
- 8.19 It would have been very convenient for the purposes of this review if we had discovered widespread support for simply transferring the ILF funding and remit to local government with a view to boosting Direct Payments and playing more smoothly into the emerging Individual Budgets agenda. The arguments against transferring ILF funding and responsibilities to local government tend to be based upon negative perceptions of the latter rather than positive support for the former, but we have found them difficult to ignore. We appreciate the concerns about the potential loss of a dedicated source of funding at a time of huge financial difficulty for local government, and despite a strong rationale to the contrary **we therefore recommend that no immediate transfer of ILF funding and remit is given to local government.**

ILF and Individual Budgets

The Importance of the IB Programme

- 8.20 The Individual Budget (IB) programme has been briefly outlined in Section 1, and given our remit to look at the ILF in the light of the changing policy context it is inevitable that the ILF-IB relationship is given greater scrutiny. It is clear that the IB concept is central to the Government's quest for 'personalised welfare', has high political significance and – unless the evaluation findings are very pessimistic – will be rolled-out nationally over the next few years. This all adds up to a major challenge which is currently being addressed in the thirteen IB pilot sites.
- 8.21 These sites are being asked to explore radical new approaches to the delivery of support while largely operating within existing structures and systems. The prevalent culture of the existing service system is strong and the challenge is reflected in the 'risk logs' of sites which identify:
- the challenge to care managers and other professionals of a significant change in their practice;
 - providers' ability to respond quickly to new demands;
 - introducing self-directed support approaches while complying with statutory policies and procedures.

- 8.22 Six resource streams, of which ILF is one, are in the pilot programme and without major changes people are likely to continue to experience multiple assessment, planning, charging and monitoring regimes, and very limited scope for creativity about how to deploy the budget to get better outcomes to meet need. Such problems have also been identified by the Care Services Improvement Partnership in its reporting from across the pilot sites. Each of the resource streams has its own procedures and rules that create these complexities, and without the ability to adapt procedures it will be difficult to explore the potential that could arise from real integration of funding at an individual level. Our starting point, therefore, is that it is vital that the ILF plays a full and committed role in the development of IBs.

ILF and the IB Pilot Programme

- 8.23 In written evidence to us the ILF states that:

“The ILF is an active and central player in the IB pilots which aim to ensure that distinct government funding streams both current and future such as the ILF can be synchronised in the interests of disabled people.”

- 8.24 In interviews we did indeed hear testimony that ILF representatives have shown a high degree of commitment and involvement in the IB pilot sites. At these meetings a wide range of issues has been identified as to how the ILF engagement might be more effective, and where ILF has deemed it possible to resolve these issues it has done so. This evidence is very positive and the ILF is to be commended for the way it is engaging with this new and complex agenda. Nevertheless, in some important respects, progress has been inherently difficult. We have been told of problems of both practice and principle, and this is perhaps reflected in the commitment of the ILF to synchronicity rather than integration.
- 8.25 Problems of practice have arisen where the legal or financial constraints upon the ILF have made progress difficult. We were told in interviews that tensions had arisen about the extent to which ILF money could be used flexibly such that self-determined care could be attained, and this seems to be reflected in the recent DWP paper that reviews progress across 36 key issues.⁴ In written evidence to us, Gateshead Council – one of the IB pilot sites – said that: “if the ILF tries to maintain its current processes and rules it will act as a brake on the development of IBs.”
- 8.26 Some took the issue even further, however, and felt this inflexibility called into question the very role and existence of ILF. This position was taken by, for example, the In Control programme, who in written evidence to us said:
- “At present the ILF system does not give people any useful sense of their entitlement. The process of claiming ILF funding is presently inconsistent with the shift to personalised budgets, and it is not clear that there is any coherence to the ILFs role.”

- 8.27 Since we have not felt able to simply recommend that ILF monies be integrated with local authority budgets, then we are left with the difficulty of how ILF can best be integrated within the IB programme. If the IB implementation programme was at a more advanced stage than other immediate options might be open to us, but in the interim we can only recommend that ILF continues to commit itself to the development of IBs. The advent of a new Trust Deed along with the possible implementation of other recommendations made elsewhere in this report should give the ILF much greater flexibility to be a good partner in this important policy programme. The ILF, in written evidence to us, has itself expressed the wish for a closer relationship with its partners, and has sought permission to behave in a more flexible way. We share these aspirations for the ILF and, pending the further development of IBs, **we recommend that the ILF synchronise its system of funding as closely as possible to that of LAs in the IB pilot sites, making maximum use of whatever new flexibilities arise in the near future.**

The Intersection with the NHS

The Current Situation

- 8.28 The place of health services in supporting independent living for disabled people is by no means an issue that is confined to the ILF, but it is legitimate for us to include the position of the NHS in our review since it does affect ILF users. The starting point here is that within much independent commentary and political discourse it is now widely acknowledged that it is artificial and unhelpful to divide the needs of severely disabled people into ‘health’ and ‘social care’ components.⁵ In complex cases the likelihood is that both contributions will be needed, and this is in line with the thrust of official exhortation to focus on a ‘holistic’ view of service user needs.
- 8.29 The major difficulty with integrating health care into the personalised welfare agenda is that current policies exclude NHS monies from being part of ‘cash for care’ programmes. The official position is that where an individual has an identified health need which falls to the NHS, that part of any care package cannot be delivered as a cash payment within the meaning of the legislation, including where a local authority is acting under a partnership arrangement pursuant to section 31 of the Health Act 1999. The stance of the community services White Paper⁶ on the principle of extending cash for care arrangements to the NHS was that “this would compromise the founding principle of the NHS that care should be free at the point of need” [para 4.39].
- 8.30 It was not uncommon in the course of our review to learn of dissatisfaction with this situation. In the view of one respondent, the NHS had yet to understand the nature of new policy approaches:

“There is more money in health budgets but they are dealing with the same things with social care money being used to purchase health, by default. I think that people in health policy are lagging behind, and partly because they

are not used to thinking about the end user – it's just not their model for social care policy.”

- 8.31 The current approach clearly causes difficulties in other parts of the system such as the ILF where eligibility is locked into the local authority contribution, and also sends out some contradictory signals. In written evidence, Leicester City Council put the problem succinctly:

“At present ILF treats funding from LAs and the NHS very differently and requires absolute clarity between the two. However, as partnership working, pooled budgets and care trusts have increasing impact, the practicality and desirability of maintaining this distinction are increasingly hard to justify.”

- 8.32 Derby City Council also commented on the fact that “the ILF rules do not permit the counting of any health money towards the contribution threshold of £200” and remarked that the real issue here was about “the anomaly of charging for one type of service but not another, this type of split is inconsistent with joint working and independent living policy initiatives.”

Continuing Health Care

- 8.33 The difficulties of distinguishing between health and social care needs have been especially sharply defined in the controversy around eligibility for fully-funded NHS continuing health care. Repeated legal challenges have culminated in the Department of Health developing a national framework for eligibility⁷ that was issued for consultation in June 2006. Under these proposals eligibility for NHS continuing health care would not depend on it being provided in a particular location, and while it will often be provided in a nursing home or hospital setting, there are also circumstances in which the NHS will be responsible for the full costs of care for someone in their own home. The NHS is responsible for the entire costs of a person's care where it is judged that there is a primary health need, rather than such needs being incidental or ancillary to the provision of accommodation, and of a nature which an authority whose primary responsibility is to provide social services can be expected to provide.⁸ Where this is the case the person would no longer be eligible for social care and if they had previously been in receipt of ILF they would no longer qualify since there would be no local authority contribution. This raises significant questions for the ILF and its interface with the NHS.

- 8.34 Concerns about the inconsistent and harmful effect of this situation surfaced repeatedly in evidence we gathered and received:

“Things have been set up and they don't necessarily fit together very easily. You have got individuals who are receiving funding from the ILF who are assessed by the NHS as having care needs beyond what social services can provide and this loses them their ILF funding.”

“The exclusion of NHS funding for disability support is ambiguous in the context of pooled budgets and adds further complexity.” (In Control)

“Someone with a terminal illness can be supported by the LA and ILF, but if they become so ill that they receive full health funding in the community this means they will lose LA money and ILF, and therefore their directly employed staff. This can mean that successful packages which have kept users in the community for years with good quality tailored care have to be changed to ‘Health’ solutions which users often don’t want and are imposed upon them in the final stages of their lives. This seems unethical and can be more expensive.” (Penderels Trust)

- 8.35 As a relative told us in a written submission, the sudden change in financial responsibilities for a person’s care can have highly undesirable (and often unanticipated) consequences:

“..last year she was assessed by the NHS under continuing care criteria and assessed at level five. This entitles her to free health and social care. However this has caused many problems both with social services and the ILF (...) because of the NHS assessment her ILF support was abruptly suspended and no further payments were made.”

- 8.36 Without proper attention this situation looks set to worsen as cash-strapped LAs and PCTs look to pass over responsibilities rather than address the holistic needs of service users. It has been reported, for example, that councils are taking legal advice on ceasing responsibility for service users who should be receiving NHS continuing care,⁹ regardless of whether or not they actually are receiving it, and this will in turn have a knock-on effect to ILF support.

- 8.37 In the midst of these policy contradictions, there is growing evidence that service users are seeking their own means of addressing the artificial policy divide between their health and social care needs. Some of the direct cash funding appears to be de facto used for ‘health’ purchases. Glendinning et al,¹⁰ for example, document how some users receive ‘health related’ care through their personal assistants for support that is no longer available from the NHS. The disabled people who took part in this study did not distinguish between ‘health’ and ‘social care’, seeing both as part of their overall ‘personal care’ needs. Indeed, some users were purchasing a range of ‘mainstream’ health services such as physiotherapy, injections, dressings, foot care, tissue care, bowel and bladder management and alternative therapies for pain management.

- 8.38 We do not believe it is possible for the Government to sustain this artificial distinction between health and social care in respect of independent living for disabled people. The debate may well be muddied by outmoded perceptions of the nature of social care – as one respondent remarked to us in horror, “..somebody in the Department said to me ‘well of course health is about what you need and social care is about what you want’ No it’s not!” In written evidence to us, ILF has asked for clarification of how in all circumstances ILF and LA funding and charging for social care relates to health, and we support this request.

- 8.39 One of our respondents said of the role of NHS funding in independent living, “It’s like the elephant in the room; sooner or later that debate has to be opened.” We agree. The development of the Expert Patients Programme in the NHS along with the Expert Carers Programme flagged up in the community services White Paper implies a reappraisal of the issue of who knows best what the needs of patients are and how they should be addressed, especially for people [such as most ILF users] suffering from long term conditions. Some commentators take the view that the extension of cash payments to at least some aspects of NHS care would improve the flexibility and value of support,¹¹ and we would support this argument. The major policy blockage here is that the NHS is largely free at the point of use, whilst social care is subject to means-testing, and this issue needs to be openly debated. In general our view is that the prime issue is how best to meet the acknowledged needs of disabled people rather than reify the budgetary boundaries of government departments.
- 8.40 **We recommend that the relationship of NHS funding to Individual Budgets be re-appraised by the Department of Health with a view to incorporating community health services into IBs. In the interim we recommend that ILF users who become eligible for continuing care should not automatically cease to be eligible for ILF support simply because responsibility for their care has transferred from local government to the NHS (and this would be possible under the 2006 Trust Deed for a period of up to 12 weeks).**

Summary

- 8.41 In this section of the report we have looked at some of the key partners and programmes with which ILF has links. We have noted the ways in which the processes and procedures of the ILF and LAs continue to lack synchronicity and have urged improvement in these respects. More fundamentally we have examined the scope for transferring the functions and budget of the ILF to LAs and we have reported the high level of expressed concern that this may result in the loss of dedicated funding for the support of independent living. Accordingly we have felt the need to recommend that in the short-term at least the ILF should not be integrated with local government. Finally we have explored the anomalous position of the NHS in relation to cash for care programmes and we have recommended that there should be a move towards incorporating community health services into the Individual Budget programme.

References: Section 8

¹ Department for Work and Pensions [2001], *Independent Living Funds: Quinquennial Review 2001*. London.

² Department for Work and Pensions [2001], *Independent Living Funds: Quinquennial Review 2001*. London.

³ Independent Living Funds [2006], *Strategic Plan 2006-2009*. Nottingham

⁴ Department for Work and Pensions (2006), *The ILFs within the Individual Budget Pilots*.

⁵ House of Commons Health Committee (2005), *NHS Continuing Care*, Sixth Report of Session 2004-05, HC 399-1.

⁶ Department of Health (2005), *Our Health, Our Care, Our Say*.

⁷ Department of Health (2006), *National Framework for NHS continuing healthcare and NHS-funded Nursing Care in England*, Consultation Document

⁸ R Vs North and East Devon Health Authority ex parte Coughlan (1999).

⁹ Community Care 5-11th October 2006, p 8

¹⁰ Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. and Tyer, J. [2000], New Kinds of Care, New Kinds of Relationships: How Purchasing Affects Relationships in Giving and Receiving Personal Assistance, *Health and Social Care in the Community* 8[3], pp 201-11

¹¹ Glasby, J. and Hasler, F. [2004], *A Healthy Option? Direct Payments and the Implications for Health Care*. NCIL/University of Birmingham

Section 9: Openness and Accountability

Introduction

- 9.1 In Section 11 we will explore the accountability of the ILF in terms of its corporate governance and departmental reporting arrangements; here, however, we examine accountability in broader terms and particularly how the ILF approaches its accountability to its customers and to other key stakeholders.
- 9.2 In recent years there has been a considerable shift in the expectations that people have of organisations in terms of their openness, responsiveness and accountability. This is a development that has occurred both in commercial and public sectors, and increasingly an organisation needs not only to be responsive to its customers, but to be seen to be responsive. We have previously outlined the changing discourse on disability and this is also highly relevant to the environment within which the ILF must operate. As we have argued, people with disabilities do not expect to be treated as passive recipients of services; rather they wish to exercise choice and control and to be fully engaged as partners with the organisations with which they have ongoing contact. The paternalistic charitable model is no longer acceptable, and its replacement with a more participative model presents major challenges. In this section we will explore the ways in which these are being addressed by the ILFs.
- 9.3 As we have observed at many stages of the report, the ILF had its origins in the social security system. The decision to establish the ILF as a discretionary fund, administered by a Board of Trustees was very controversial from the outset, resulting in some deep divisions within the disability community and the beginning of a campaign to create an alternative system that eventually culminated in Direct Payments. As one witness said to us, “it is a creature of its time that was hastily cobbled together.” What this political haste has also produced is a particular style of organisation that, in the view of some people, has come to be seen as increasingly anachronistic and anomalous.

The role of the Trustees

- 9.4 We were surprised in the course of the consultation meetings to discover how little awareness service users and their families have about the role – or indeed the existence – of trustees within the ILF. The trustees appear to have a very low profile and to have made little impression on most ILF customers – in our review of the consultation event findings, we reported that there was very little awareness of how the ILF operates as an organisation.

- 9.5 Some of our witnesses and respondents were highly critical about the role and remit of trustees, particularly about the relative absence of disabled people and ILF customers from the Board, as the following comments illustrate:

“There was a lot of criticism at the time about the way the ILF was set up as a kind of charity (...) and there was a lot of argument about representation on the Board of Trustees (...) But they resisted that, and you know its 2006! We were making those arguments when it was first set up!”

“Then there is the thing about being accountable to the people who use the service. They have to construct a system, however they do it (...) So the question is whether the Trust Deed is the appropriate vehicle for their governance, or should it be something else?”

“Why are trustees doing this job? I mean – I don’t know what their motivation is, I’m sure its all good but (...) a small group of people appointed by the Secretary of State to administer an awful lot of money, and not really accountable to anyone!”

- 9.6 The Board of Trustees has considerable power. The fact that Trustees operate within a discretionary framework means that they have substantial leeway, and in exercising this discretion they make use of their own solicitors and counsel. While the DWP advises the ILF Trustees (particularly on Trust Deed matters), it is not able to provide legal advice because of the requirements of the regulation of the legal profession.

- 9.7 The Glasgow Centre for Inclusive Living (GCIL) and Scottish Personal Assistant Employers Network (SPAEN) made a joint written submission to the review and summed up the difficulties that arise:

“The ILF effectively replaced a statutory system based on entitlements, transparent assessment, appeal procedures, case law and the opportunity for legal challenge, with a charitable system dispensing discretionary payments.”

- 9.8 The meetings of the Board of Trustees do not take place in public, and minutes of the meetings are not made available via the ILF website. Furthermore, there are no regular opportunities for ILF customers to meet Trustees or to have the chance to question them about matters of policy. This is in contrast to the routine practice of many other NDPBs, and drew very harsh comment from some of our respondents:

“There is a bit of the ‘we know best what you need dear.’”

“Do you remember Spitting Image with the BBC board sitting around a table covered in cobwebs? That’s my sort of impression.”

- 9.9 The ILF told us that they recognise that Trustees can appear rather remote from service users and there is an intention to organise more user events that Trustees might attend and to hold the first ever ‘open meeting’ with Trustees. **We recommend that the ILF should improve the accessibility of its Board of Trustees and should provide opportunities for ILF customers to meet members of the Board on a regular basis. We further recommend that**

Board meetings should be conducted in public, and should include opportunities for questions from the public, and that minutes of the meetings should be published. This is consistent with practice in a number of other NDPBs and public bodies (for example, the General Social Care Council, Primary Care Trusts, and local authority council meetings, it is also a practice which is consistent with the principles of public life identified by the Nolan Committee in 1995). We see no reason why public meetings should compromise matters of confidentiality and if there are confidential issues that need to be considered by the Board it should be possible to organise the meetings to allow for a closed session where this is judged essential.

Engagement with service users

9.10 The wider engagement with service users is a further aspect of openness and accountability which must be addressed. This is an important issue not only because of the need to operationalise an ideological commitment to user-directed care, but also because organisations like the ILF which are not accountable through local democratic processes need to be structured in ways that demonstrate accountability and responsiveness to service users. In such circumstances it will be necessary to demonstrate that service users are involved and engaged with the organisation, and play a key role in reviewing and shaping activity.

9.11 The Strategic Plan issued by the ILF for 2006/09 identifies five major priorities for the next three years; the first of these is:

“We will have promoted better outcomes for users by effectively listening and using their experiences to inform our plans and practices.”¹

Four outcomes to be achieved by 2008/9 are accordingly identified:

- our judgements about the service we provide will include a more appropriate contribution from the actual experiences of those people receiving ILF monies;
- active consultation will have been undertaken with users and their representative organisations on process and policy change;
- users views will be represented within our key written publications;
- we will be able to show that our users believe we make a positive difference for them as a result of the change in emphasis for this ethos.

9.12 We welcome these aspirations, but, we are not convinced that the ILF has established the necessary policies and practices to ensure these will be achieved. The ILF states that it “has made good progress in the last 5 years with the development of a user consultation group and user road shows in

different parts of the country but we recognise the need to do more.” We are not persuaded by the claim that ‘good progress’ has been made, and we are concerned that this may indicate either an unacceptable level of complacency, or a lack of understanding of the nature and significance of the issue, or both.

The ILF User Group and Consultation Processes

- 9.13 No one who participated in the review consultation events had any knowledge or awareness of the ILF User Group. As we reported, it was clear that our own consultation meetings were the first opportunity that most ILF users had ever had to discuss their experiences. The ILF User Group was established in September 2001. As far as we have been able to ascertain this was the first time in the history of the ILF that any such consultation process had been established.
- 9.14 At the time of the Quinquennial Review work had just commenced on establishing the user group, and this was welcomed by that review. The initial intention was that the group would be piloted with clients within a 50 mile radius of the ILFs’ offices at Nottingham, and following an evaluation this approach would be extended throughout the UK. This has not happened. The user consultation group has failed to progress beyond the pilot stage, and now appears to be moribund. After an initial surge of interest, attendance was disappointing – of the membership [said to be between 10 and 15], the maximum attendance during 2005 was only six. Exercises were carried out to attract new members but it was reported that none of the prospective new members had attended during that year. In May 2005 the Chair of the Group also resigned.
- 9.15 Initially the User Group was planned to meet every two months, but at the request of the ILF this was reduced to four meetings a year in 2005 on the grounds that inter alia the Client Liaison Manager faced additional work in trying to expand and extend approaches to user consultation. No activity of the User Group has been reported on the ILF website since November 2005. Written evidence submitted to the review by the Spinal Injuries Association identified the ILF’s engagement with service users as a key weakness and observed:

“The ILF Users Group appears to be failing. At the last meeting held in the ILF Office Nottingham only 3 people attended, with 3 apologies. This could be perceived as a major failing regards the impending DDA public duty legislation requiring public bodies to engage with users.”

This concern was echoed more generally in written evidence from Gateshead Council which observed that:

“Given the focus nationally on the involvement of disabled people in the planning of services, the involvement of ILF users in the running, development and monitoring of the ILF is very poor.”

9.16 We are fully aware of the practical and operational challenges which surround good quality user engagement and consultation. Moreover, we recognise that for an organisation such as the ILF whose customers often have significant levels of disability, the logistical difficulties of gathering people together for meetings are considerable. However, these are not insuperable, and there is a wealth of good practice that has been established by others also addressing such challenges, not least by user-controlled organisations such as Shaping our Lives. The principle that service users should be involved in decisions that affect them is fundamental and is reflected in the now well-used slogan: 'Nothing about us, without us'.

9.17 The ILF told us that they recognised the difficulties and shortcomings of the user consultation process they had established and that they were currently refocusing the approach and looking at a completely different type of consultation strategy. In future the intention is to move away from a single User Group and to constitute different groups as required to comment on specific areas of work. At the same time work is also planned to monitor user satisfaction. We would raise a note of caution here: user satisfaction surveys are notoriously unreliable as indicators of service quality; they are a blunt instrument and something altogether more sophisticated is required to explore user experiences. Qureshi and Henwood's exploration of older people's definitions of quality services for the Joseph Rowntree Foundation commented:

"Individual satisfaction with services may relate strongly to expectations (and the information that users have about services), therefore those who expect little may be satisfied with services which others may judge to be below the standards which should be expected." ²

9.18 Accordingly, the use of satisfaction surveys can lead to a false sense of complacency and a belief that services are performing well when in fact they are far from satisfactory.

9.19 It is not only the methods of ILF user consultation that have had serious shortcomings; it is also the manner in which the user group was constituted which raises some major concerns. The user group was set up with the following remit:

- "To give individual feedback on their experience of the Funds and suggest improvements to service.
- To consider and comment on current and future changes to Funds' literature and how this might impact upon users (this does not include comment on the nature of the information required by the ILF but does include how the information is requested).
- To advise on future development of service and procedures for service users.

- The group is not a lobby or pressure group and the group initially will not be involved in discussions on policy or developing links with other service users.”

We find the constraints on the activity and interest of the user group both astonishing and very disappointing. To impose such boundaries on the group from the outset suggests a lack of clarity about the purpose of a user group, and implies an organisation that is nervous about scrutiny and criticism, and overly-defensive - which was also an impression reflected by a number of respondents and witnesses.

- 9.20 We were surprised to read in the ILF’s Consultation and Inclusion Strategy (contained within the ILF’s Disability Equality Scheme document) the claim that the user group “continues to meet in order to assist the organisation with the development of policies and plans.”³ As we have remarked above, the user group has ceased to meet and when it did meet it was prohibited from addressing matters of policy. We understand that the User Group has been replaced by ad hoc mechanisms to consult on specific issues as required. When we discussed the User Group within the consultation events ILF customers were clear that any user-involvement process should be genuinely consultative, not tokenistic or inappropriately constrained. As one person remarked: “we want an alternative user group – not an ILF fan club.”
- 9.21 Some of our witnesses were similarly surprised by the boundaries imposed on the activity of the user group as this comment illustrates:
- “I think that’s an absolute disgrace, I really do. Because one of the things that we are about now is making sure that users are consulted fully (...) across the board – that is just such an important thing.”
- 9.22 We are also concerned about the stark control exercised by the ILF on the membership of the group. The guidelines on the Client User Group published on the ILF’s own website state that the Chairperson of the user group will be appointed by the Chairman of the ILF Board of Trustees. The remainder of the group will be drawn from users invited to take part and “agreed by the Chairman and ILF Information and Service Director.” There may have been concerns that an open-access and self-nominating user group could be susceptible to ‘take over’ by particular interest groups, but we see no justification for restricting the opportunities for people to take part in the user group in this way. In the event the ILF have told us that no ILF users who applied to join the User Group (i.e. those who were invited because they were within 50 miles of Nottingham) were refused; however, we remain concerned about the tone of the guidelines and the underlying assumptions which these seem to reveal.
- 9.23 It would be easy to dismiss the user consultation strategy to-date as mere tokenism and to have little faith in any substantive change of direction. However, we accept that the ILF does want to improve its user-involvement and become more user-focused. If it is serious about improving its approach, some major changes are required. This is not simply about adjusting the consultation machinery and processes. It is about something much more

fundamental in terms of the organisation's understanding of, and engagement with, the user movement and the disability community.

- 9.24 Five years have passed since the embryonic development of user consultation within the ILF, and we do not believe that the pace of change that has been achieved in these years is acceptable. We recognise there are plans for change, but at present these are insufficiently formulated for us to judge their likely success. The Strategic Plan states that it will "expand user consultation and liaison activity with the delivery of a targeted consultation plan." However, our conclusion is not merely that consultation needs to expand, but that it needs to be fundamentally different in kind.
- 9.25 Some of the respondents who submitted evidence to the review made suggestions about other ways in which service users might be better engaged with the ILF. For example, it was suggested that an interactive message board, or 'chatroom' would be a useful addition to the website, and might provide opportunities for other ILF users to act as 'mentors' to new or potential ILF users. We believe such innovations merit consideration, but suggest that this should be approached within a wider strategy.
- 9.26 The Consultation and Inclusion Strategy presents a number of objectives which are summarised in Box 9.1. We welcome these plans. However, we note that almost all of these objectives are for new activities and future plans rather than the consolidation of an already well-established record of user involvement. The ILF was assessed for the Government's Charter Mark standard for customer service excellence in October 2006 and was awarded Charter Mark status in November. There is clearly some dissonance between our own conclusions on user involvement and the judgements of the Charter Mark assessors, and we are not in a position to explain these differences. We are, however, surprised that the assessors commented that:

"The degree of user involvement and engagement appears to be high and this has led to real changes in the way that services are delivered, making them better able to meet service users' needs."

The evidence we gathered in our review does not support such a conclusion.

- 9.27 We are pleased that there is recognition within the ILF of the need to secure "a more appropriate contribution from the actual experiences of those people receiving ILF monies", but we remain uncertain about the vision and capacity of the organisation to deliver it, and we believe that it needs considerable support to do so. **We recommend that the ILF commissions a user-led organisation (such as Shaping Our Lives or similar), to work closely with the ILF to advise on the establishment of a comprehensive and multi-faceted user involvement and consultation strategy. We further recommend that the ILF improves its wider customer engagement and accountability processes by consulting with the ODI and working closely with the National Centre for Independent Living and local CILs as appropriate.**

Box 9.1

ILF Action Plan for User Consultation and Inclusion

Over the next three years the ILF will:

- Conduct at least two full user surveys to benchmark satisfaction levels and assess any changes in performance.
- Develop a methodology of regularly monitoring user satisfaction at key processing stages.
- Further explore the scope of holding regional User Group meetings.
- Establish an ILF Advisory Group to enable users and key stakeholders to engage in much greater detail with the formulation of ILF policy.
- Continue to conduct partial surveys in response to specific policy/process needs.
- Consider further road-show events at key national locations.
- Explore the possibility of creating on-line discussion forums on key topics relating to ILF activity.
- Introduce an annual ILF 'Open Meeting' to enable direct engagement with ILF Senior Management and Trustees.
- Establish on-line survey facilities to enable more effective use of the ILF website.

Source: ILF (2006), Disability Equality Scheme 2006-2009, Appendix 3 'Consultation and Inclusion Strategy.'

The Disability Equality Duty

- 9.28 Addressing user involvement is no longer simply a matter of good practice; it is also now a legal requirement. The Disability Discrimination Act 1995 (DDA), as amended, introduced new rights for disabled people, and redress against discrimination, in their contacts with the public sector and with employers. However, it is evident that the implementation of the Act has not been sufficient to overcome individual disadvantage because as the ODI has pointed out, many organisations "take a tactical approach to compliance" and do the minimum possible simply to avoid legal action rather than focusing on genuinely delivering improved outcomes for disabled people. Equally, if the needs of disabled people have not been adequately understood or built into policy and service design, the response will be inadequate.⁴ Because of these shortcomings the Government has introduced a new duty on public authorities through the Disability Discrimination (Amendment) Act 2005 "to

have due regard to the need to promote equality of opportunity for disabled people (the Disability Equality Duty).”

- 9.29 The Disability Equality Duty (DED) requires public authorities to carry out their functions with ‘due regard’ to the need to:
- “Eliminate unlawful discrimination and disability-related harassment.
 - Promote equality of opportunity for disabled people, taking steps to take account of disabled people’s disabilities.
 - Promote positive attitudes to disabled people, and
 - Encourage disabled people to participate in public life.”⁵
- 9.30 In addressing the new DED, regulations require specified public bodies to produce a Disability Equality Scheme. This requirement came into effect on 4 December 2006. Failure to comply with the DED could result in a compliance notice being issued by the Disability Rights Commission, and enforcement procedures are available through the court system.
- 9.31 The ILF is not currently listed in regulations, but has nonetheless complied with the DED requirements by publishing its Disability Equality Scheme on 4 December 2006. The document welcomes the DED not simply as a legal obligation “but as a great opportunity to promote equality, inclusion and independent living for disabled people.”⁶ We welcome the positive response from the ILF and we endorse their desire to continue to improve service “by listening and learning from the experiences of our users.”

Summary

- 9.32 In this Section we have examined the openness and accountability of the ILF in terms of how it relates to service users. We have acknowledged the aspirations of the ILF to improve its consultation and to reflect on the views of service users in shaping policy and practice. However, to recognise that such improvements need to be made should not be confused with believing they have already been achieved. We have identified considerable shortcomings in the approach to user involvement to-date; consultation has been selective and in many respects tokenistic, and there have been inappropriate constraints placed on the role and remit of the User Group.
- 9.33 We welcome the plans the ILF has identified for improving its approach to consultation and user engagement. However, we do not believe that plans alone will be sufficient to ensure delivery. The limited success of the ILF in this area in the past points to the need for expert advice and support in taking this agenda forwards. We have strongly recommended the active collaboration of the ILF with a user-led organisation to support and refine the consultation and inclusion strategy.

References: Section 9

¹ ILF (2006), *Strategic Plan 2006-2009*, ILF: Nottingham.

² Qureshi H and Henwood M (2000), *Older People's Definitions of Quality Services*, York: Joseph Rowntree Foundation.

³ ILF (2006), *Creating Choice for Disabled People. Disability Equality Scheme 2006-2009*.

⁴ ODI (2006), *Disability Equality: A priority for all. Guidance for Civil Servants on the duties imposed by the Disability Discrimination Act*.

⁵ Ibid, para 5.

⁶ ILF (2006), *Creating Choice for Disabled People. Disability Equality Scheme 2006-2009*, P,14.

Section 10: The ILF's Legal Framework

- 10.1 We have referred throughout this report to the ILF's legal framework created by the Trust Deeds and the Conditions of Grant Agreement (COGA). At the time of our review the ILFs were in a state of limbo as they waited for a new Trust Deed to come into effect and for a new COGA to be agreed. The timing of the new Trust Deed was conditional on the Parliamentary timetable and the need to exploit the opportunity offered by the Welfare Reform Bill. The fact that a new Trust Deed has been prepared in advance of the report of the ILF review may appear to limit our scope to make recommendations for further changes to the Trust Deed where we believe these may be required. In fact, the opposite is the case and the new Deed creates a platform for future changes and flexibility and could allow early action on many of the recommendations.
- 10.2 In this Section we consider the limitations which have been imposed on the ILFs by the legal framework, and the extent to which these are being eased by the revised Deed.

The Trust Deeds and COGA

- 10.3 We have remarked at various stages in the report on the unusual NDPB arrangements of the ILFs. The existence of a Trust is almost unique; while there are numerous NDPBs in operation, no others are comparable to the ILFs in featuring a Trust that was set up by Government and continues to operate. The nearest parallel is the VCJD (Variant Creutzfeldt -Jakob Disease) Trust that was established by the Department of Health, although unlike the ILFs this operates completely independently of Government.
- 10.4 The ILF Trust was originally only intended to have a five year life span (as we outlined in Section 1). In the early 1990s there was external pressure to put a scheme on a statutory footing, but this was resisted and the 1993 Fund was established as a new Trust. Since 1993 the ILFs have therefore operated under two separate Trust Deeds – the Extension Fund Deed and the 1993 Trust Deed. It has become increasingly cumbersome to continue to operate two Trust Deeds (with separate accounting and reporting requirements, one of which – the Extension Fund – is also covered by Charity Commission requirements), albeit under the governance of a single Board of Trustees. A new Trust Deed has been prepared and its implementation is contingent on Royal Assent for the Welfare Reform Bill (expected by July 2007). This will effectively provide a unified Deed covering both ILFs. The new Trust will not have charitable status. The new Trust Deed can be seen in many ways as a streamlining process which seeks to integrate the two previous Deeds into a more rational arrangement. In future (pending legislative approval) there will be one set of accounts, one set of reports, and one set of trustees.

Streamlining the Trust Deed

- 10.5 Most of the changes within the new Trust Deed have been made for reasons of clarity or in order to update the Deed in line with other policy and legislation. Other changes are those required in the governance arrangements for an NDPB. In particular, the Fourth Schedule of the Deed addresses the functions and responsibilities of the Chief Executive, including those as Accounting Officer for the ILF.
- 10.6 Further revisions to the Trust Deed have been made to address anomalies that have become evident over the years (such as inconsistencies between the Trust Deeds and the COGA), and in response to requests from the ILF Trustees. The new Trust Deed also specifically allows that no one should be barred from being a Trustee “by reason of his or her being a Candidate or a relative of a candidate or by reason of any payment having been made by the Trust to that person or for his or her benefit.” Previously the 1993 Fund did not allow beneficiary Trustees, while the Extension Fund did allow for this (by way of a Charity Commission scheme). We welcome the new flexibility to allow beneficiary Trustees. We noted in Section 3 that ILF users favoured such an arrangement and most supported the idea that a majority of Trustees should have personal experience of disability. **We recommend that at the earliest opportunity the Board of Trustees should have a majority of disabled people.**
- 10.7 We have referred previously to the £200 threshold sum that is required as a local authority contribution to the care package of recipients of the 1993 Fund. The new Trust Deed does not fundamentally review the level of this sum (and we have also recommended that it remains at £200), but it does allow this to be calculated over a year rather than having to be a fixed amount every week. We welcome the fact that since October 2006 the 1993 Deed has allowed for annualisation of the local authority contribution – subject to there being regular and ongoing payments -and believe this more accurately reflects the varying needs and patterns of support for service users over a period of time.
- 10.8 There is a similar flexibility with regard to the maximum sums payable. Although there is no change to the actual maximum sums (i.e. £785 per week combined LA and ILF contribution and £455 ILF contribution), Clause 3(i)(c) states that Trustees may use their discretion to:
- “..pay more than the Maximum Sum in any week or weeks in a Financial Year provided that they are reasonably of the opinion and take reasonable steps to ensure that the total of the sums paid to or for the benefit of that Candidate over that year will not exceed either (i) the Maximum Sum for a Candidate of that group multiplied by 52 or (ii) (if less) that Maximum Sum multiplied by the number of weeks in that year in which in the reasonable opinion of the Trustees that Candidate is likely to be eligible to receive financial assistance from the Trust.”
- 10.9 We welcome the flexibility offered around the calculation of the Maximum Sum, in both the Trust Deed and the COGA although we reiterate our

concerns about the inappropriateness of the Maximum Sum in principle which effectively excludes people with the highest needs from eligibility.

- 10.10 We recognise that there are tensions within the Trust Deed. The DWP has a prime concern to ensure financial propriety and that a sizeable budget is being spent in the way that is intended; these objectives can be in some tension with the ILF's wish for less prescription and more flexibility. The new Trust Deed therefore represents a compromise between these two. A further area of tension is that between increased flexibility and reduced transparency. The greater discretion that is allowed Trustees under Clause 3 enables payments to be made for "the sort of liability that might properly be incurred in order to obtain Qualifying Support and Services required to assist that Candidate to Live Independently". This should allow Trustees, for example, to pay for such things as national insurance, holiday pay, transport, recruitment costs etc. We welcome this opportunity, but we are concerned that leaving Trustees to determine what is and what is not reasonable may mean that the decision making process of the ILF becomes more opaque. We have already recommended in Section 6 that the ILF makes it clear to ILF customers and potential applicants that it will normally make payments to cover the on-costs that may be associated with obtaining the required support and services. We believe that the spirit of the new Deed is that this should be stated as a matter of policy rather than only being addressed on an individual basis.

Modernising the Trust Deed

- 10.11 The new Deed is more than simply administrative housekeeping; there are also some substantive changes that have been introduced to modernise the ILF and its operation, and specifically to make it more flexible. The most significant changes in this respect are firstly that the new Deed adopts a definition of independent living which is closer to that contained in the Life Chances report from the Strategy Unit, and secondly that "personal care and domestic assistance" is replaced by a new definition of "qualifying support and services."
- 10.12 The concept of qualifying support and services currently updates the list of personal care and domestic assistance (but also includes a new condition referring to supervision to avoid substantial danger to him or herself or others). However, the definition is intended to be flexible and refers to "those types of support and services as may from time to time be prescribed in the Grant Conditions." This could allow in future for the list to be expanded to include other aspects of support around independent living. This would not require further changes to the Deed, and this would therefore be a policy decision rather than a legal one (as is currently the case). The Secretary of State has powers within the new Deed to make any amendments, with or without the consent of Trustees. Significantly, the new Deed also gives new powers to the Trustees (with Secretary of State's prior consent) to amend parts of the Deed, but also to amend some parts of it, for some people, for some purposes. Clause 18 therefore states that under certain specified conditions:

“The Trustees may from time to time amend the Trust by revoking or varying any of the trusts powers or provisions of this Deed (whatever their nature and including the Schedules) or by adding any new clause, either generally, or with respect to a specific group of people and for a specified time period so as to enable the Trustees to take part in pilot schemes.”¹

10.13 We welcome the flexibilities of the new Trust Deed, and **we recommend that the revised conditions of grant agreement should expand the definition of qualifying support and services in order to address support needs beyond the narrow confines of personal care and domestic assistance (for example, leisure activities and community participation). Elsewhere in this report we have identified the particular changes that need to be addressed to support independent living more comprehensively.**

10.14 In the course of the review we frequently encountered objections to the constraints of the current Trust Deeds. As we have noted previously, this was identified as a particular issue in the Individual Budgets pilots, as these respondents observed:

“I think the problem now is what they can and can't do is causing a few problems in some of the pilot sites (...). It's basically about how flexible they can be in terms of what they would class as personal care.”

“It's so hamstrung that it can't do anything imaginative and creative anyway.”

“There are issues about the definition of 'personal care' and what the money can be spent on. It's as if the ILF defines things in terms of the service rather than the outcome to be achieved.”

10.15 The ILF's written submission to the review also identified the difficulties which have arisen from trust deeds that “were set up in a very different era before the current social care scene and disability strategy had been contemplated.” The ILF told us that they recognise the difficulties which service users experience with the ILFs, and the barriers to working effectively with Individual Budgets, and emphasised that:

“The difficulty with moving forward on all these issues comes not from lack of will from the ILF but from legal restrictions, existing DWP expectations, funding availability, and only slowly emerging certainty about best methods of self-directed support ...In these circumstances the ILF has been careful not to declare values and aspirations that it cannot match with delivery, and which could embarrass our parent Department.”

10.16 However, some of our other witnesses and respondents were less sure that the ILF Trust Deeds were so significant in limiting the remit of the ILF and were dubious about the ILF responding positively to the flexibilities available in the new Trust Deed, as these comments illustrate:

“It gives them powers around piloting, which is a step in the right direction. But I can't imagine them suddenly jumping into action – let's get a pilot going

now! I don't know if they are actually planning anything; I would like to think that they might be."

"I remain suspicious that they aren't actually – they don't give the impression that they are pushing at the boundaries of the Trust Deed, that they are trying to create flexibility. It looks more as if they are trying to control flexibility, which is a rather different approach."

- 10.17 The ILF needs to be aware of this perception among its partner organisations. The ILF tends not to be perceived as an organisation which is eager to make changes and is actively planning to take up the opportunities offered by piloting powers. Rather, the dominant view that we encountered was of the ILF frequently referring to its inability to respond differently because of the Trust Deeds:

"It's not 'well, we would really like to do this but it is difficult in the current context and we are hoping we can shift things', which is a different kind of approach, or 'maybe we can try it out on a smaller scale'."

- 10.18 We do not deny that the framework created by the Trust Deeds has placed particular constraints on the activity of the ILF. However, we agree with many of our respondents that the impression given by the ILF is not of an organisation that is eagerly anticipating the opportunities of the new Trust Deed and ready to move ahead in taking up the new flexibilities at the earliest opportunity. We were informed by the ILF that Trustees had considered some ideas for piloting at the Board meeting in November 2006. However, this discussion is at a very early stage and much greater clarity is needed in exploring the purpose of piloting and the legitimate areas in which this can take place without inappropriately moving into policy territory in which the ILF has no legal remit.

- 10.19 **We recommend that the ILF should prepare and disseminate a strategy for making use of the piloting powers that should be available from summer 2007. The strategy should explore a range of issues where piloting could be beneficial and should prioritise those it wishes to pursue via a business case under the new Deed.** We believe not only that this is the right course of action for the ILF in preparing for the new Trust Deed, but that this would also be an important symbolic statement that would demonstrate the ILF's commitment to modernisation and improved partnership working.

Summary

- 10.20 The new Trust Deed for the ILF that is contingent on Royal Assent being granted to the Welfare Reform Bill is a welcome document. The Deed offers a much needed (and long overdue) rationalisation and streamlining of two parallel Deeds which have operated for the Extension Fund and the 1993 Fund. Consolidating and integrating these two documents has an obvious appeal. The new 2006 Trust Deed will go further than merely 'tidying up' such

administrative inconvenience and goes a considerable way to creating the preconditions for a more flexible and responsive ILF to develop, and to remove many of the impediments which have previously existed. The extent to which this will happen in practice will depend in large measure on the initiative and vision of the Trustees and ILF Executive Team, and we have recommended that appropriate strategies are developed immediately to indicate their commitment to pursuing the new opportunities offered around piloting.

- 10.21 The 2006 Trust Deed creates a more permissive legal framework than hitherto. We have indicated areas where we believe further easement is necessary and where matters might be addressed through conditions of grant agreement. The new Trust Deed gives express powers to the Secretary of State to specify the Trust period and to revoke or change any such specification. The Trust period for the Deed will end on the fifth anniversary, or at a later date specified by the Secretary of State, but in any case on a date no later than 31st March 2026. This arrangement ensures that the Secretary of State does not have an open-ended commitment to maintaining the Trust Deed. We believe this offers a welcome opportunity for change that may be required further down the road. As we will explore in greater detail in Section 12, the future of the ILF needs to be considered both in terms of the next few years, but also more strategically in the longer term.

References: Section 10

¹ *Trust Deed, Dated 10 April 2006, The Independent Living Fund (2006)*, The Solicitor to the Department for Work and Pensions.

Section 11: Strategic Framework: Corporate Governance and Reporting

- 11.1 In this section we examine the ways in which the ILF is governed at national level, how far these reporting and accountability arrangements have supported operational and policy work, and whether there is a case for changes to these arrangements. Currently the ILFs are funded by, and report to, the Department for Work and Pensions (DWP), but the work of the ILFs is also of considerable significance for the Department of Health (DH) and, to a lesser extent, other central government departments in England. In principle a coordinating role in respect of disability issues is held by the Office for Disability Issues (ODI) which is located in DWP. However, the position of the ILFs is further complicated by its UK remit, which means there is an interest held in the Northern Ireland Executive, and on the parts of the Welsh Assembly and Scottish Parliament.

Departmental Accountability

- 11.2 The current pattern of accountability of the ILF to DWP was rarely questioned during the course of our review. Although this arrangement may simply be the continuation of a historical relationship originating from the social security roots of the ILF, it is now bolstered by the presence of the Minister for Disabled People within DWP. We heard a number of positive messages from some respondents on the appropriateness of the DWP-ILF relationship:

“DWP see themselves as the champions of disabled people and they actually do that quite well; they are much more positioned with the mainstream.”

- 11.3 It was also pointed out to us that the Public Service Agreement targets of DWP are concerned with equality for disabled people – “personal assistance should be seen as a means to an end, and DWP is actually charged with that end.” Certainly we heard no strong case being mounted for removing responsibility for ILF to any other central department. The only possible alternative would be the DH which has responsibility for Individual Budgets and therefore has a strong interest in the activity of the ILF. Again, we discerned no strong interest on the part of DH in taking on such a responsibility, and indeed we were told on several occasions by some respondents that this might be a retrograde step because “social care is forever the junior partner of the NHS within DH.”

- 11.4 An additional perceived problem with DH was the view that it has a narrow conception of independent living rooted in a traditional notion of social care as these comments reveal:

“When I think about social care and social support services I tend to think about them from a very broad perspective, whereas in DH they tend to think in relation to social care legislation which tends to be around keeping people clean and fed, getting them up and putting them to bed at night.”

“(the DWP has) an advantage in that when we talk about independent living, we don’t immediately think ‘social care’; we tend to think about employment and being able to live autonomously.”

“..the Department of Health is always assumed by the rest of government to look after older people and disabled people, and it’s about the care element. And if we are serious about independent supported living, it should be outside us, because we do do the care bits and support bits.”

- 11.5 A further worry about locating accountability for the ILF within DH is the central level parallel of the problem we identified earlier in handing responsibility to local government – the threat to the continued ring-fencing of the funding for disabled people:

“If ILF had been part of DH you can imagine that it could easily have been absorbed - particularly with Direct Payments coming in - into a sort of generic social care subsidy to local authorities, and it would have vanished.”

- 11.6 However, the view that the DWP is the right place for responsibility for the ILF to be located should not be taken to imply that the ILF-DWP relationship could not be improved. Some witnesses suggested to us that although the ILF-DWP arrangement had been administratively satisfactory and opened up the prospect for a broad dialogue based around the 2005 Life Chances Report ¹ it had tended to be weak in terms of nurturing and development of the ILF – “safe but not developed” as one respondent put it, and as another remarked in respect of the relationship with the ILF, the DWP “has behaved with benign neglect really.” Indeed, we were told that the focus of the DWP tended to be on financial accountability at the expense of strategic thinking about the role of the ILF and where it might sit in any future policy constellation. Where this is the case then it is not satisfactory, but the very fact that this independent and external review has been commissioned by DWP is at least some sort of testimony to the department’s wish to think strategically about the ILF. **We recommend that central accountability for the ILF remains with the Department for Work and Pensions.**

Inter-Departmental Coordination

- 11.7 Although it is important for central accountability that the ILF is located in the most appropriate department of state, it is now widely accepted that policy on independent living cannot be the preserve of any single department – the range of income streams currently contained within Individual Budgets is a practical manifestation of this truism. The perennial question for all such cross-cutting issues is how to secure inter-departmental coordination?
- 11.8 We are only too well aware of the history of ‘joined up government’. From the days of the Central Policy Review Staff and the Joint Approach to Social Policy in the mid 1970s,² right through to the quest of New Labour for ‘joined up government’ and the establishment of the Performance and Innovation Unit

and the Social Exclusion Unit, it is a chequered – indeed troubled – history. In the case of disability policy the coordinating mantle and the responsibility for guiding implementation of the Life Chances report falls to the recently created Office for Disability Issues (ODI). We found the ODI to be exceedingly well informed about the issues surrounding the ILF and passionate about the potential for independent living more generally. As we noted in Section 1 an ODI Review of Independent Living has been established and will report in summer 2007.

- 11.9 Like all previous inter-departmental vehicles, ODI has to rely upon the power of persuasion vis-à-vis state departments, and it is not evident how effective this tactic will be or how long ODI has got to establish its credentials. The obvious danger is that departmental intransigence may limit the role and effectiveness of ODI, and this would be an unfortunate development for disability policy and for disabled people. There is the additional problem that a unit established under the auspices of the Prime Minister's Strategy Unit may be too closely associated with a specific administration and may not find favour with a different Prime Minister.
- 11.10 Some of these issues are obviously well outside the remit of this review, and we raise them as important matters that need to be discussed and decided elsewhere. Nevertheless, there does need to be a close link between the ODI (and especially the Review of Independent Living), DWP and ILF, and we hope that our review will be a helpful contribution to the discussion. The location of ODI within DWP is helpful in this respect. **We recommend that the findings of this review be 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.**

The UK Dimension

- 11.11 The ILF remit runs across all four nations – England, Northern Ireland, Wales and Scotland – and – as we have noted at various points in the report - this raises additional complexities for our review. We have been asked to examine the position of the ILF in a changing policy environment, but this environment differs in important respects across the nations. The most significant differences are that at present only England is developing Individual Budgets and also has Direct Payments; Wales, Northern Ireland and Scotland do have Direct Payments (at different stages of development and implementation) but not Individual Budgets; Fair Access to Care charging policies only apply in England, and finally – in Scotland free personal care is provided. It is therefore very difficult for us to form a conclusion on the ILF that applies only to England and not to the other three nations.
- 11.12 Our starting point is that in principle there is no inherent impediment to having an Individual Budget agenda in all four countries. Glasgow City Council's submission to the review pointed out that while Individual Budgets are a

Department of Health initiative “not, as yet, UK-wide”, nonetheless, Glasgow were “keen to embrace the principles of Individual Budgets and explore their true potential.” Moreover, our Consultation Events in Belfast, Newport and Edinburgh gave us every reason to think that this would be in line with the wishes of disabled people in those countries. Accordingly, our fundamental concern is not whether or how ILF ‘fits’ across the four nations, but rather a presumption that disabled people in Scotland, Wales and Northern Ireland have as much right as those in England to have a policy on independent living and ‘cash for care’ that is consistent with the framework of values we have developed in this report. Indeed, we have already noted some discontent in Northern Ireland that in the absence of ready access to Direct Payments the local authority contribution towards ILF may consist of unwanted traditional services.

- 11.13 We have encountered some criticism of the ‘Anglo-centeredness’ of ILF. In written evidence to us, again Glasgow City Council stated that:

“Generally there is a bias towards English/DH legislation rather than a more inclusive UK perspective. This is an obvious source of confusion for customers and practitioners alike and requires urgent attention. Examples include the introduction of free personal care in Scotland only and implementation of Fair Access to Care in England alone. The latter causes an obvious difficulty in applying a UK wide charging policy.”

- 11.14 A further difficulty is the absence of an ILF presence in the other nations apart from visits by ILFAs, which leaves users in these countries feeling that they are governed remotely from England. We are aware that the ILF has plans to assume a multi-national presence. In evidence to us the ILF proposes an additional geographical dimension to the ILF organisation structure:

“to create regionally based staff perhaps for each of England (N) England (S) Wales/Northern Ireland and Scotland who are able to draw together and link networks of users, providers, LAs, ILFAs, and Nottingham based ILF staff.”

- 11.15 We support this suggestion, but we are disappointed that it has taken such a long time for such a proposal to even get to this stage. **We recommend that the ILF reviews all of its documentation to ensure it is appropriate to the different national contexts within which it is used. We further recommend that measures to establish an ILF presence across the English regions and other nations of the UK be urgently progressed.**

- 11.16 The extension of an Individual Budget model to the other nations is especially difficult in relation to Scotland where the Scottish Parliament has responsibility for housing, health and social care, but Westminster retains responsibility for income streams related to employment. The Scottish Executive [SE] has actively invested in expanding the take-up of Direct Payments through the establishment of Direct Payments Scotland, although funding for this project ceased in March 2006. In her report for the Scottish Executive, Witcher³ concludes that the SE approach to DPs would not necessarily conflict with Individual Budgets for disabled people, but that careful thought would have to

be given to the implications of free personal care for older people. She identifies four options:

- **do nothing:** it is unclear here what would become of UK wide budgets [including the ILFs] that cover Scotland if these are subsumed into IBs in England but not in Scotland;
- **combine all budgets:** the key issue here would be whether Westminster or the SE took responsibility; if the former an amendment to the Scotland Act might be needed, given that it would absorb some reserved budgets;
- **incremental approach:** SE could bring together only the budgets that it controls, building incrementally on existing action;
- **single assessment:** establish mechanisms for a single assessment with a case manager bringing together different strands of funding from budgets that remain separate.

11.17 These are matters of practicality, whereas our concern in this section of the report is with issues of principle. In this respect the recent Report of the Disability Working Group⁴ in Scotland proposes a vision that sits well with our approach. The congruence can be seen with several key principles and proposals:

- that the Scottish Executive agrees and publishes a set of principles based on the social model of disability to underpin the work of all departments;
- that without independent living full citizenship 'is but a distant dream' and that the SE should consult disabled people on how it can be supported nationwide;
- access to independent advocacy is critically important and should be supported by the SE;
- independent living means having the same choice and control over your life as non-disabled people do.

11.18 The report refers to the Individual Budget programme in England and to the difficulties created by two Parliaments having responsibility for different components of the IB 'pot' and notes that "it remains to be seen how this will be resolved." We are inclined to go a little further and say that the interests of disabled people should not be affected by where they happen to live in the UK. We note the recognition in the 21st Century Social Work Review⁵ that 'doing more of the same won't work', and additionally note that In Control Scotland has now been established to promote the development of Individualised Budgets and Self Directed Support. Further, we understand that fresh Guidance on Direct Payments that will reinforce these trends will shortly be issued by the Adult Support and Protection Unit in the Scottish Executive.

11.19 Our view is that the momentum for Individual Budgets and Self-Directed Care is not confined to England, and our belief is that opportunities for independent living should be maximised in all parts of the United Kingdom. Strictly speaking it is beyond the remit of our review, however, **we recommend that Individual Budgets be piloted in Scotland, Wales and Northern Ireland as a matter of urgency and that an appropriate quadrilateral group is established across the four nations to guide the coherent development of policy on disability and independent living.**

Summary

11.20 In this section we have examined the reporting and accounting arrangements relating to the ILF. We have noted the current line of accountability to DWP and, despite some logic in replacing this with accountability to DH, we have recommended retention of the link to DWP. However, we have also emphasised the need for inter-departmental coordination, and expressed the wish for a close working relationship between the ILF, DWP and ODI. There are complex differences in cash for care arrangements across the UK and they impact upon the operation of the ILF. We believe there should be greater consistency across the UK and we propose that Individual Budget pilots commence across Scotland, Wales and Northern Ireland.

References: Section 11

¹ Cabinet Office [2005], *Improving the Life Chances of Disabled People*. London. Prime Minister's Strategy Unit.

² Central Policy Review Staff (1975), *A Joint Framework for Social Policies*, London: HMSO.

³ Witcher, S. [2005], *Improving Life Chances Report and Individual Budgets*. London. Scottish Executive

⁴ Scottish Executive (2006), *Report of the Disability Working Group*.

⁵ Scottish Executive (2006), *Report of the Recommendations made by the 21st Century Social Work Review Group for the Future of Social Services in Scotland*.

Section 12: The Future Organisation Recommendations and Conclusions

12.1 In this final section of the report we have three tasks:

- to highlight the assumptions that underpin our conclusions;
- to pull together all of the recommendations that we have made throughout this report;
- to place these recommendations in a wider vision for the future development of policies on independent living.

Underpinning Assumptions

12.2 In considering the future direction of the ILF as an organisation we are guided by a number of underpinning assumptions. These are:

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

Doing nothing is not an option

12.3 It is clear from the recommendations already made in this report that we see a need for change to the rules and procedures of the ILF – a very considerable revision of existing arrangements. However, we do not think it sufficient to simply ‘tidy up’ existing anomalies; there is also a need for a much more substantial consideration of where or whether the ILF fits into future strategies on independent living. We have taken cognisance of the recent report by Sir David Varney¹ on the broader issue that is at stake here. In the 2006 Budget the Chancellor asked for advice on the opportunities for transforming the delivery of public services by looking at how the channels through which services are delivered can be made more responsive to the needs of citizens and businesses.

12.4 One of the key points made in the Varney Report is that “each solution is a child of its time and circumstances, with little overarching view of the Government’s relationship with the citizen” (p1). This observation neatly encapsulates the constitutional position of the ILF – an organisation created in haste to solve a particular political problem at a particular point in time. To

make such an observation is not to decry the contribution that has been made by the ILF over the past 18 years, but simply to establish that what might have been appropriate for the 1980s is not necessarily right for the rest of the current decade and beyond.

- 12.5 We received a great deal of evidence to the effect that a ‘root and branch’ approach to the future is necessary – that doing nothing (or proposing minor tweaking) in this respect is not an option. In written evidence, In Control put the point strongly:

“It is unclear why there should be so many different bodies all responsible for providing support funds to disabled people and with no organising rationale. The multiplicity of overlapping assessments by different bodies and different systems seems to be both wasteful and confusing.”

Edinburgh City Council in similar fashion bemoaned the way in which:

“The interaction of all the current individualised care funding systems in the community, predicated on distinct but overlapping criteria, forms a web of interwoven uses that become more dense with every policy shift and refinement.”

- 12.6 This is an important point, and we would not wish to make recommendations that simply create ever more complexity and confusion. On the basis of the evidence we have received there seems to be a strong body of opinion that finds it puzzling to have dual systems of support in operation:

“It is difficult to understand why we have a parallel system of ‘direct payments’ administered from Nottingham. No matter how skilfully and benevolently that system is operated it imposes an additional set of administrative requirements on disabled people.” (Service User)

“It doesn’t make sense to have two different systems (local and national) which are allocating cash to service users, especially when they have overlapping but incompatible eligibility criteria.” (Bath and NE Somerset Social Services)

“Yet another assessment for users to go through leading to confusion about where money comes from and who they should go to about what. Part of a bigger unjoined up maze disabled people have to navigate.” (Penderels Trust)

- 12.7 We do not believe an administrative tidying up can adequately address these concerns, and we support the general position taken by Derby City Council that ‘all resources in connection with supporting independent living must have a common framework for allocation’. Doing nothing in this respect is not an option.

No loss of service and no overnight change

- 12.8 In Section 2 we explored the inequity of access that is a feature of ILF, emphasising the unacceptably high degree of randomness as to whether people with similar needs are receiving support for independent living. Indeed, we went further and suggested that those with the very highest needs are currently excluded from access to the ILF. One option open to us would be to recommend that some people currently in receipt of ILF should lose some of this funding in order to accommodate those with equal or greater needs who are currently excluded.
- 12.9 In written evidence to us, the ILF said that “the support packages of 18k users are lifelong and a critical factor in their lives as citizens and should not be threatened.” We agree with this, and our assumption is that there should be no loss of service for people currently in receipt of ILF – a stance we made clear during our Consultation Events. At the same time, this should not be taken to infer that change should not take place across the broader system or that existing and future ILF users will remain outside of any such change. Rather our mission is to propose a set of arrangements that will command support across the spectrum of the disability community.
- 12.10 In attempting to identify such arrangements it is doubtful if anyone would choose to start with the current fragmented situation, but we have to accept that we are where we are. It does not seem to us very sensible to propose any radical sweeping away of the ILF unless and until a better alternative exists. Although we accept that this will take time, we do not accept that the time scale should be such that the future organisation of the ILF is kicked into the political long grass. The need to both protect existing users and have a clear timescale for fundamental organisational change constitutes our second assumption.

Second guessing emergent policy change

- 12.11 A critical part of the commissioning of this review of the ILF has been to consider the ILF in the wider and emerging policy context around ‘cash for care’ programmes – a challenging requirement. If a clear blueprint on the future of social care was available then our task would be simpler, as one respondent observed:
- “I think the most important question for the ILF is this bigger context ‘what kind of strategic decision has been made about Social Care?’. And without some clarity about that, your question becomes very difficult to answer. But if you know that then the ILFs role is almost quite a secondary thing isn’t it? “
- 12.12 Throughout our fieldwork there was frequent acknowledgement of the difficult timing of this review:
- “I think the timing for you is really, really difficult. I would say that in 18 months time if we knew where Individual Budgets were really going and we had the

report from the evaluation and we knew how successful they had been, then you would have a very clear roadmap.”

- 12.13 Age Concern, England observed that “it is perhaps unfortunate that the review has fallen so early in the pilots” for Individual Budgets, and cautioned that “it may be premature to make radical alterations to the ILF at this point in time.” Although the direction of travel does look reasonably clear, what is less evident is how fast, how far and how reliably this journey will be undertaken, and whether the destination will be markedly different across the four countries of the UK. One response to this predicament would be to conclude that we cannot make any realistic judgement about the future, and therefore we cannot propose any substantial change on the future of the ILF. This seems to be the position supported by the ILF itself, which in written evidence to us, says:

“It seems likely that the Review will only be able to go so far and that some of the most important issues such as roles and responsibilities of all partners and charging of clients can only be resolved through later and wider reviews. Joint consideration will be needed on many issues between DWP, DH and DCLG and with the LAs – and involving separate discussions with administrations in Scotland Wales and Northern Ireland. A precise long term role for the ILF may be impossible to specify through this Review given that considerable uncertainty will continue around means testing, available funding levels, the future of IBs, the boundary between health and social care, and the boundary between people above and below ‘retirement age’.”

- 12.14 This position seems rather close to that of the Isle of Wight Social Services who suggested to us that “any review of the arrangements should be made during a time of policy stability, not whilst policies are changing.” Tempting though it might be for us to shelter behind this position, we believe we would be failing in our task if we did so. Notwithstanding the policy turbulence that currently characterises personalised budgets, we feel it is incumbent upon us to make the most informed judgement we can about a preferred and attainable future, and to locate the position of the ILF within this judgement. This constitutes our third assumption.

Value-based reform

- 12.15 Finally it is important that we return to where we started in this review – to restate our commitment to value-based change, and to be explicit about the nature of these values. In Section 2 we identified six key values against which we would make our assessment, and these have guided us throughout the review. As we proceed into the very final part of the review we believe it is important to restate these values:

- **Equity:** the extent to which people can get the help they need to fulfil their role as citizens; equity between all people needing help, so that some client groups are not favoured over others.

- **Transparency:** the extent to which people know how much money they are entitled to spend in order to make plans for their lives; and clarity over how those decisions are made and can be challenged.
- **Accessibility:** the extent to which the rules and systems are negotiable and proportionate, and the extent to which the system is publicised and applications encouraged.
- **Self-Determination:** the extent to which people have the authority, support or representation to make their own decisions.
- **Flexibility:** the extent to which people are free to spend their funds in ways that make most sense to them, with minimal interference.
- **Values and Outcomes:** the extent to which the system is geared towards what people value and achieve in terms of an improved quality of life and user-defined outcomes

An overall judgement that reflects these values constitutes our fourth and final assumption.

The Future Organisation

12.16 Cabinet Office guidelines on the review of NDPBs identify several possible options:

- abolition;
- agency status;
- NDPB status;
- contracting out;
- market testing;
- merger or rationalisation;
- privatisation.

12.17 As we have noted elsewhere in this report, the ILF is an unusual, if not a unique, NDPB given that it has a large customer base receiving weekly cash payments funded by the Government. This makes some of the above options inappropriate, and in our view the choice is between two of the options – continuation of existing ILF structure (as currently classified as an NDPB) or merger/rationalisation.

Continuation of Existing ILF Structure

- 12.18 Throughout this review we have found opinion about the ILF to be deeply divided, with some polarised views being put to us. Our task has been made even more complex by the difficulty in distinguishing between the preferences users have for the principle of ‘cash for care’, as opposed to support for the ILF itself as the right organisational vehicle. These differences are perhaps most pronounced in respect of the future status of the organisation. Not only have we found opinions ranged for and against the continuation of NDPB status; we have also discovered a wide spectrum of strength of opinion.

The Case for Retention of Current ILF Structure

- 12.19 For some people the great attraction of retaining the ILF structure is the continuation of some sort of national system of support – another reaction against the variability and fragility of LA services and support. Inverclyde Centre for Independent Living, for example, identified a number of advantages of retained NDPB status including independence from DWP and LAs, the lack of stigma attached to ILF applications and a suggestion that clients felt more secure with an ILF award. However some witnesses, in forming their views on the desirability of NDPB status, seemed to have an exaggerated perception of the autonomy of the ILF. The written evidence we received from Scope, for example, argues:

“Another positive aspect of ILF being administered by an NDPB is that it remains flexible and able to give an element of choice and control for the service user. By having an NDPB in control it helps in its independence and is not restricted. It should theoretically be able to point out to Government that more action is needed in terms of improving the funds, and by having autonomy it is easier to set appropriate aims.”

- 12.20 In reality the ILF has much less autonomy than some people seem to imagine (as we explored in Section 10), though some witnesses took the view that the ILF should have a much wider, and hence more powerful, remit. Hampshire Centre for Independent Living, for example, told us:

“The ILF is a country-wide payment and is unaffected by local government politics. It is far less bureaucratic than social services and more realistic about accountability. It might be preferable to take Direct Payments away from social services and place them in the hands of the ILF.”

- 12.21 The ILF itself appears to concur with this view. In written evidence to us it proposed a considerable expansion of its own role and remit:

“The Review is bound to want to consider whether the ILF might take a stronger role... There may be mileage in the idea of the ILF taking on an additional role to help drive up DP delivery in the interests of faster expansion of the programme, and at the same time secure greater consistency... the ILF is already responding to this changing context and we believe is now seen by

its more informed partners as central to the emerging social care agenda. .. However if the ILF is to maximise its contribution against this changing policy context it needs to be repositioned on several dimensions through adjustments to its legal basis, closer working with a number of different government departments, functions, client group, and charging structure – in order to take full account of contextual changes already underway... we could operate exclusively on the model in place before 1993 without sharing funding with LAs, perhaps meeting and funding all personal needs rather than PDC alone... there are potential attractions in combining the ILF funding for care at home with DWP funding for support at work in circumstances where one support person can perform both roles.”

The Case against Retention of Current ILF Structure

- 12.22 We have already highlighted the concerns felt by many witnesses about the extent of overlap and duplication between the various cash for care programmes and this is part of the case put forward by those who oppose retention of NDPB status for the ILF. Other issues were also raised with us, however, including a strong view that the status of the ILF is an anomalous hybrid that no longer has a place in the 21st century:

“I think it is unique in several ways because it is very rare. I’m not sure if there is another example of a Trust that was set up and is still running by the Government. The ILFs are a kind of quirky example of something that doesn’t quite fit in to the standard model of something that gets done.”

“The whole philosophy now seems to be to reduce the number of arms length bodies. If someone was doing something like the ILFs now I’m sure that it wouldn’t have been done in that way.”

“My gut feeling is that the ILF is intrinsically anomalous. It is anomalous; but it has value.”

- 12.23 In written evidence to us Birmingham City Council pays tribute to the pioneering work of the ILF but feels the time has come for fundamental change:

“ILF Nottingham was an excellent forerunner of cash for care and helped set the scene for future models. However, its policies and procedures are now out of line with LAs across the country and the time has probably come for either an overhaul or disbandment of the Fund.”

- 12.24 For one respondent the problem with the status of the ILF is that it is a hybrid of an arm of Government and a large voluntary organisation that ends up falling between these stools:

“The thing is obviously a hybrid, It is not quite one thing and not quite another. It feels a bit like one of the giant service delivery charities which just so happens to be entirely funded by Government, but the charities can be quite creative in the way they operate because they determine their own future a lot

more. The ILF can't create any new sources of income for itself and the Trust Deeds are fairly inflexible."

- 12.25 Others were even more emphatic about the need for fundamental change. A user-led London-based charity, Independent Living Alternatives, simply argued that "the future lies in sourcing all money from one pool and developing Individual Budgets for all disabled people." The London Borough of Brent weighed up the situation and concluded: "While respondents are able to identify a number of strengths, on the whole the comments seem to point to the view that the ILF is becoming increasingly outmoded." And the judgement of Glasgow City Council was trenchant:

"It is hard to imagine how such a body could continue to function effectively in the face of significant legislative and cultural change. Local control, public accountability and independence need to be the way forward. Unless effective change is achieved for the ILF we will have missed a significant opportunity and lost the current momentum for radical change."

- 12.26 We share the view that it is anomalous to leave significant public monies for social care in the hands of a cash-limited, discretionary fund administered by a Board of Trustees in Nottingham, with all of the implications for inequity, lack of accountability, overlap, duplication and confusion for disabled people that we have documented in this report. This conclusion rules out the possibility of ILF assuming a more significant role (such as in taking over the administration of Direct Payments). However, since we have already recommended against a simple transfer of ILF resources to local government, it will be necessary to retain the ILF for the time being until an alternative model is more fully formed. This future model will be Individual Budgets which are planned (subject to evaluation) to be rolled out nationally from 2009/10. **We recommend that the ILF retain their current structure until at least 2009/10 at which point a further decision should be taken in the light of developments in other parts of the independent living system, but with a presumption of full incorporation into the Individual Budgets programme thereafter.**

- 12.27 The fact that we are linking our recommendations for the ILF so strongly to the anticipated development of Individual Budgets which are still being piloted may cause some surprise. However, whatever the precise results of the IB evaluation, it is evident that the concept of personalisation of care and support is one which attracts support across the political spectrum and among service users and their carers. Whatever the precise form personalisation will take (whether this will be through IBs or an as yet to be determined model), it is clear that this will be the way forward. It will not be possible (and certainly not desirable) to turn back the clock; public expectations have been raised and the future direction will be one based on personalised, flexible and responsive support which maximises individual autonomy and control.

ILF: The Future Organisation

- 12.28 The immediate future for the ILF is effectively contained in the cumulative recommendations that we have made throughout this report, all highlighted in bold text. These are separately reproduced below. The effect of these recommendations would be, if implemented, to bring to the ILF all -and more - of the flexibilities it has been seeking. These will be important changes that we hope will take effect over the next few years. These changes will greatly improve the equity, transparency, accountability and accessibility of the ILF. We believe such improvements must be made and indeed the moral case is compelling, but we do not believe that this can offer a medium or longer term alternative to our preferred option of a smooth transition to comprehensive integration.
- 12.29 Some of our recommendations are for immediate action by the ILF itself and do not require significant new resources; others are for the ILF to work as an excellent partner with other agencies; and others still are for the attention of Central Government, including the main service departments (DWP and DH) and the Treasury. In some cases we have proposed time limits on implementing these recommendations, in other cases we have not, but our overall view is that the time span for putting into effect these medium term recommendations should be a maximum of five years (to coincide with the anticipated roll out of Individual Budgets), and often much less. We note the budget allocation for the ILF for 2007/08 and the increase of 13% in the total budget (GB only) to £288.439m (of which £9.889m is for administration purposes – an increase of 11.5% gross). We hope that this will enable the ILF to address some of the recommendations we have made requiring immediate action, which we recognise will not be without resource implications. Full implementation would be far from cost-free and we appreciate that the 2007 Comprehensive Spending Review will be tight and we have not made our recommendations lightly or without regard to their cost implications. However, as we noted in our introduction, we have taken the view that our task is to identify a sustainable and value-based vision for independent living; it is for others to make decisions about resource availability and relative priorities.
- 12.30 **However, we do not wish to see the ILF expand (beyond those areas we have identified such as support for people aged over 66 and those on middle rate DLA) and become entrenched as a parallel system of social care support in the longer term.** Throughout this report we have identified the difficulties that this dual system creates for disabled people and professionals and although we have found several instances where the practice of the ILF has been less than satisfactory, the real issue here is the constitutionally anomalous position of the ILF.
- 12.31 **We believe the most desirable medium term goal for the support of independent living is full integration of personalised budgets** – in other words that the current funding streams (and any additional future streams) are incorporated into a single unified system. This means one funding stream, one RAS, one assessment, one charge and one system of monitoring and accountability. Retention of the ILF as a separate source of social care

funding is currently slowing down progress towards this goal even though ILF is a willing partner within the limits of its manoeuvrability. The attainment of fully integrated personal budgets would leave the ILF looking even more anomalous than at present.

- 12.32 As noted earlier, most of the IB pilot sites have been using one of the In Control RAS models as their starting point, and these offer a potential national framework for resource allocation, and are applicable to both working age adults and older people. This is consistent with our earlier recommendation that the prospects for a national RAS be urgently examined – the existence of 150 different local RAS systems would result in a major post code lottery and an absence of portability. Moreover, this version of RAS is based on self-assessment which we have also supported as an appropriate future model. We appreciate that further work needs to be undertaken here, and that the IB evaluation should come up with some important findings, but **we reiterate our support for the development of a national RAS to underpin a national system of individualised support.**
- 12.33 There is the further issue of responsibility for the administration and delivery of integrated personalised budgets and we see no realistic alternative to placing this responsibility upon local authorities. In time we expect and hope that local Centres for Independent Living will emerge more strongly, and it may then be possible for greater responsibility to be vested in the user-led constituencies and in the development of social enterprise bodies. In the meantime, we need to avoid a rerun of the FACS scenario in which LAs have the discretion to ration eligibility for support in ever-decreasing circles.
- 12.34 As we have already recommended above, there needs to be a National Resource Allocation System that gives disabled people certain assurances that wherever they live they will receive equal consideration and support. In this respect we are proposing that independent living for disabled people be put on the same footing as is being suggested for continuing health care, with a national framework that is administered locally. In this way we would hope there would be a greater degree of equity and portability of support than is currently the case. **We recommend a national framework for the local administration of personalised budgets.**
- 12.35 As an interim measure towards full integration, the goal must be the maximum degree of synchronicity between ILF and its partners, notably LAs. We have, at many points in this report, indicated where this needs to happen – in eligibility criteria, in support planning, in charging and in monitoring and review. The recommendations we have made should have the effect of increasing the ability of the ILF to synchronise its procedures with LAs more easily than at present. **We recommend that the ILF in conjunction with DWP and DH draw up an immediate strategy for maximum synchronicity of ILF resources for personalised budgets pending incorporation into a national framework.**

Conclusions

- 12.36 We will not be using our concluding remarks to reiterate points already established in the body of the report – these are all summarised at the end of this section. Rather we wish to take the opportunity to reaffirm our main judgement on the task we were set, namely to consider the organisational future of the ILF in the light of recent and emerging policy trends. Our starting point has been to adopt an appropriate framework of values and principles within which to form judgements. We then comprehensively identified the changing ideological and policy context, and sought to locate ILF in that context. In addition we have examined the more immediate operational issues that beset the ILF. In undertaking these tasks we have drawn upon a very wide range of different types of evidence. It is important therefore to emphasise that our overall judgement is both value-based and evidence-based.
- 12.37 The ILF has played a significant part in the short history of independent living. Its achievements over the last eighteen years or so have been important, and under our proposals the ILF will have a continuing – indeed growing – role in the immediate future. Several of the recommendations we have made are consistent with those proposed by the ILF themselves in written evidence to us, as indeed they reflect the totality of the evidence submitted to the review. We have indicated at various points in the report where the ILF has made the case for improving access; developing better support for independent living; addressing anomalies in charging; and improving overall synchronisation with local authorities. On previous occasions the ILF has put these arguments to the DWP and asked for the necessary change in legal remit and additional funding necessary to support these extensions. Many of the recommendations we have made would – if implemented – provide the ILF with the wider role it has sought. However, our overall view is that it is inherently anomalous to have a separate NDPB responsible for such a large amount of social care funding, and operating to different rules and remits. The move towards IBs means that this incongruence will be further heightened and, on balance, we have not been convinced of the case for a separate and continuing existence for the ILF beyond the medium term.
- 12.38 This means that the next and final stage in the life cycle of the ILF is to act as an excellent partner in the pursuit of full integration of personalised budgets. We understand that this will be a very difficult and perhaps painful task to undertake, but we are confident that the best interests of all disabled people wishing to live independently will take precedence over any issues of organisational existence. Our prime concern throughout this review has been to understand what sort of arrangements will be of most benefit to disabled people in their quest to have independent lives, and to make recommendations accordingly. We trust that this goal unites all of the agencies whose contribution will be vital over the coming years.
- 12.39 Finally, and for the purposes of clarity, we draw together the recommendations made throughout the report, and present them below with a clear allocation of responsibility for action, and a timeframe for implementation.

RECOMMENDATION	ACTION	TIMEFRAME
EQUITY RECOMMENDATIONS		
1. Work should begin immediately on an inter-departmental basis to estimate the cost of extending ILF to older people and planning to implement this extended access.	DWP to lead in consultation with the Treasury, and DH.	Work should begin immediately and extended access for older people should be accomplished within five years.
2. Work should begin immediately on an inter-departmental basis to estimate the cost of extending ILF to residents of long-stay hospitals and campus accommodation and former residents living in the community.	DWP to lead in consultation with the Treasury, DH and ILF.	Work should begin immediately and extended access for these currently excluded groups should be accomplished within five years.
3. Work should begin immediately on an inter-departmental basis to estimate the cost of removing the joint ceiling cap of £785.	DWP to lead in consultation with the Treasury, DH and ILF.	Work should begin immediately and full access for people with very high support needs who are currently excluded from ILF should be achieved within five years.
4. Receipt of middle rate care component of DLA should not preclude recipients from applying for ILF funding.	DWP in consultation with ILF.	Immediate.
5. ILF funding should be available to support disabled people in their parenting roles and local authority support should be considered as eligible expenditure.	DWP in consultation with ILF.	Immediate.

RECOMMENDATION	ACTION	TIMEFRAME
6. The requirement to take a partner's benefits and capital into account in assessing an ILF recipient's means should be removed.	DWP in consultation with ILF.	Immediate.
7. The apparently low take-up of ILF by black and minority ethnic groups should be investigated and any necessary action put in place. The ILF should review its current approach to working with Black and Minority Ethnic Users as part of its Disability Equality Strategy.	ILF.	Immediate.
8. The Disabled Students Grant and any student loan should be disregarded in calculating an ILF award.	DWP in consultation with ILF.	Immediate.
9. The ILF should take account of the costs which disabled parents face if their children are in further or higher education, and assessment of capital should make adequate disregard of savings for this purpose.	DWP and ILF.	Immediate.
10. Disabled people with a terminal illness and a life expectancy of less than six months should be able to apply to the ILF.	DWP and ILF	Immediate.

RECOMMENDATION	ACTION	TIMEFRAME
11. Consistency of ILF take-up should be promoted across all local authorities and parts of the UK.	DWP in consultation with ILF.	Immediate and on-going.
12. People receiving higher rate DLA should automatically be given information in appropriate formats about applying to the ILF.	DWP	Immediate.
TRANSPARENCY RECOMMENDATIONS		
13. The ILF should review and simplify its processes and information for service users, and develop meaningful performance indicators to drive improvements in responsiveness to new and existing clients.	ILF	Within 12 months.
14. The ILF should make explicit the basis for its judgements so that service users and their advisors have greater certainty about the outcome of claims.	ILF	Immediate
15. The ILF should review its training for all staff in basic customer care.	ILF	Immediate.
ACCESSIBILITY RECOMMENDATIONS		
16. When eligibility for higher rate DLA is under review ILF should continue to be paid until the review and	DWP and ILF	Immediate.

RECOMMENDATION	ACTION	TIMEFRAME
appeal procedure are complete.		
17. DWP should investigate the implications of de-coupling ILF eligibility from higher rate DLA entitlement, and should explore the simplification of ILF eligibility criteria.	DWP	Within 12 months.
18. Arrangements should be put in place to integrate the financial assessments of ILF and local authorities. In the interim, the charging system of the ILF should be brought into alignment with the approach of LAs and the guidance on Fairer Charging.	DH, ILF and LAs and IB pilots.	Within 12 months.
19. Occupational pensions should be disregarded from financial assessment for the ILF.	DWP and ILF.	Within 12 months.
20. Capital limits on savings should immediately be brought into alignment with those of LAs. This would raise the upper limit to £21,000 and the lower limit to £12,750. These limits should be subject to automatic annual uprating and should continue to match the residential care capital limits. ILF payments should also	DWP and ILF.	Immediate.

RECOMMENDATION	ACTION	TIMEFRAME
be automatically uprated in line with inflation, consistent with the Income Support system.		
21. The local authority threshold contribution should remain at £200.	No Action Required.	
22. ILF and LA partners should examine data on cost distribution of care packages and determine a fair percentage cost allocation for care packages over £575 per week.	DWP, ILF and LAS	Immediate.
23. The ILF should revisit the design and appearance of its website, and in consultation with a wide and diverse group of ILF users it should initiate appropriate redesign.	ILF	Immediate.
24. The ILF should reconsider its review of literature in consultation with a wide and diverse group of ILF users and explore whether further changes are required to improve accessibility.	ILF	Within 12 months.
25. ILF should set a target of a maximum of 8 weeks from the date of an application to reaching a decision. When this is not possible, a clear explanation must be provided to the applicant.	ILF	Within 12 months.

RECOMMENDATION	ACTION	TIMEFRAME
26. ILF clients should have their needs reviewed at least annually, and more frequently if the need arises or if requested.	DWP and ILFs	Within 12 months.
27. ILF and LA partners should address how to jointly manage reviews to remove duplication of effort and inconvenience for clients. Documentation should be simplified and suitable for on-line completion.	DH, ILF, LAs and IB pilots.	Within 12 months.
SELF-DETERMINATION RECOMMENDATIONS		
28. The ILF should urgently develop a strategy for supporting life planning for all its customers in partnership with local authorities and independent brokerage support organisations.	DWP, DH, ILF, LAs and IB pilots.	Within 12 months.
29. The commitment in the Life Chances report to creating user-led organisations modelled on CILs in each locality by 2010 should be firmly implemented.	ODI and DH	Fully implemented by 2010.
30. ILF should build on its protocol with NCIL to support capacity building of CILs in partnership with LAs via local government representative bodies.	ILF, Local government representative bodies.	Immediately.

RECOMMENDATION	ACTION	TIMEFRAME
31. Only one assessment of support needs should be undertaken. The ILF and partner agencies must identify the most appropriate way of removing duplication.	ILF. LAs	Fully implemented by end of December 2008.
32. ILF should develop a strategy to promote a culture of self-assessment among its users.	ILF, DWP and ODI.	Within 12 months.
33. ILF should undertake a review of the role and function of ILF Assessors in self-assessment.	ILF.	Within 12 months.
34. ILF should develop, in conjunction with In Control and CSIP, a strategy for identifying and addressing the obstacles to adopting RAS.	DWP, DH, ODI, IB Pilots, LAs ILF, CSIP, In Control.	Within 12 months.
35. ILF income stream should be fully incorporated into rolled out Individual Budgets.	DWP, DH, ODI	From 2009/10.
36. Government should prepare the ground for a national RAS and identify the implications for local authorities and the ILF.	DWP, DH, ILF and Local government representative bodies.	End of 2008.
FLEXIBILITY RECOMMENDATIONS		
37. The ILF should work with IB partners and other As to build on	DH, DWP, ILF, LAs, CSIP.	End of 2008.

RECOMMENDATION	ACTION	TIMEFRAME
partners and other LAs to build on the lessons from IB pilots and build a protocol for a shared accounting system across ILF and Direct Payments.		
38. Light touch approach to auditing ILF customers should be maintained, but greater attention needs to be paid to supporting people with the administration and management of finance.	ILF	Immediate.
39. Limitations on the use of ILF for personal care and domestic assistance must be revised to take full account of the wider objectives of supporting independent living.	DWP.	Within 12 months.
40. ILF should as a matter of policy recognise the on-costs of employing PAs, and of being responsible employers.	ILF and DWP	Within 12 months.
41. ILF should examine the possibility of paying a start up grant to new users to recognise the additional costs incurred in recruitment and beginning to use PAs, and in paying for advice.	DWP and ILF	Within 12 months.
42. Flexibility should be allowed in the roll-over of funds recognising	DWP, DH, ILF	Immediate.

RECOMMENDATION	ACTION	TIMEFRAME
<p>people’s fluctuating needs and the value of a small contingency fund. At minimum these roll-over arrangements should match those for Direct Payments.</p>		
<p>43. ILF should move to a system of payments four weekly in advance, instead of in arrears, at the earliest opportunity.</p>	<p>Treasury, DWP and ILF</p>	<p>Within 12 months.</p>
<p>44. ILF should be payable from the date that a properly completed application form is received.</p>	<p>Treasury DWP and ILF</p>	<p>Immediate.</p>
<p>45. DWP and ILF should be more flexible in payments around hospital admissions and should support requests from ILF users where there is a case for their needs being met by a PA while they are an in-patient. The four week period of support should also be applied more flexibly depending on individual circumstances.</p>	<p>DWP and ILF</p>	<p>Immediate.</p>
<p>46. The ILF should, in general, retain its policy of not allowing payments to relatives within the same household. However, we recommend that discretion continues to be exercised in</p>	<p>No action required.</p>	<p>Immediate.</p>

RECOMMENDATION	ACTION	TIMEFRAME
exceptional circumstances.		
LINKS and PARTNERSHIPS RECOMMENDATIONS		
47. The ILF should continue to develop customised links with LAs.	ILF	Immediate and on-going.
48. The ILF LA Liaison Team and LA Contact Officers should draw up a clear strategy (within the Data Protection Act) to maximise synergy between ILF and LAs, including coordination within LAs between Contact Officers and individual social workers.	ILF LA Liaison Team and LA Contact Officers.	Within 12 months.
49. No immediate transfer of ILF funding and remit should be given to local government.	No action required.	
50. ILF should synchronise its system of funding as closely as possible with LAs in the IB pilot sites, making maximum use of new flexibilities in the 2007 Trust Deed.	DWP, DH, ILF, CSIP.	Within 12 months.
51. Relationship of NHS funding to IBs should be re-appraised by Department of Health with a view to incorporating community health services within IBs.	DH.	Within 12 months.

RECOMMENDATION	ACTION	TIMEFRAME
52. ILF users who become eligible for NHS continuing care should not automatically cease to be eligible for ILF support.	ILF, DH, DWP.	Contingent upon implementation of the national framework for NHS continuing care.
OPENNESS and ACCOUNTABILITY RECOMMENDATIONS		
53. ILF should improve the accessibility of the Board of Trustees and provide regular opportunities for ILF customers to meet Board members.	ILF	Immediate and on-going.
54. ILF Board meetings should generally be conducted in public, and include opportunities for questions from the public, and minutes of meetings should be published.	ILF	Immediate and on-going.
55. The ILF should commission a user-led organisation (such as Shaping Our Lives) to advise on the establishment of a comprehensive and multi-faceted user involvement and consultation strategy.	DWP, ODI, ILF.	Within 12 months.
56. ILF should improve its wider customer engagement and accountability by consulting with the ODI and working more closely with the National Centre for	DWP, ODI, ILF.	Immediate and on-going.

RECOMMENDATION	ACTION	TIMEFRAME
Independent Living and local CILs as appropriate.		
LEGAL FRAMEWORK RECOMMENDATIONS		
57. At the earliest opportunity the Board of Trustees should have a majority of disabled people.	DWP.	Within 12 months.
58. ILF should prepare and disseminate a strategy for making use of the piloting powers that should be available during 2007. The strategy should explore issues where piloting could be beneficial and prioritise those it wishes to pursue via a business case.	ILF	Immediate.
59. Conditions of Grant Agreement should expand the definitions of qualifying support and services.	DWP in consultation with ILF.	Within 12 months
CORPORATE GOVERNANCE RECOMMENDATIONS		
60. Central accountability for the ILF should remain with the DWP.	No action required.	
61. The findings from this review should be considered alongside those of the ODI review of Independent Living and the recommendations taken forward jointly.	DWP. ODI.	Immediate and on-going.

RECOMMENDATION	ACTION	TIMEFRAME
62. ILF should review its documentation to ensure it is appropriate to the different national contexts across the UK.	ILF	Immediate.
63. The ILF should urgently progress the establishment of a presence across the English regions and within the other parts of the UK.	DWP and ILF	Immediate and on-going.
64. Individual Budgets should be piloted in Scotland, Wales, and Northern Ireland.	Scottish Executive Health Department. National Assembly for Wales, Department of Health. Northern Ireland Executive, Department of Health, Social Services and Public Safety (DHSSPS).	Commenced within 12 months.
65. A quadrilateral Ministerial group should be established across the four nations to address the coherent development of policy on disability and independent living throughout the UK.	DH, ODI, Scottish Executive Health Department. National Assembly for Wales, Department of Health. Northern Ireland Executive, DHSSPS.	Immediate set up and report within 12 months.
THE FUTURE ORGANISATION RECOMMENDATIONS		
66. ILF should retain its current structure until at least 2009/10 when a further decision should be made in the light of developments, but with a presumption of full incorporation into the Individual Budgets programme.	DWP, DH, ILF, Cabinet Office.	No later than 2012, contingent upon IB roll-out.

RECOMMENDATION	ACTION	TIMEFRAME
67. A national framework should be developed for the local administration of personalised budgets.	DH. DWP.	No later than 2012, contingent upon IB roll-out.
68. ILF and CSIP should draw up a strategy for maximising synchronicity of ILF resources and personalised budgets, pending incorporation into a national framework.	DWP, DH, ILF. CSIP.	Immediate and on-going.

References: Section 12

¹ Varney, Sir D. (2006), *Service Transformation: A better service for citizens and businesses, a better deal for the taxpayer* (HM Treasury)

Appendix 1: Review Methodology

The review adopted a four stranded methodology in gathering evidence, comprising:

- Announcement of the review by DWP and invitation to submit views.
- Distribution of a formal call for evidence.
- Series of consultative meetings around the UK.
- Programme of one to one interviews with central government and other national level stakeholders.

Written Submissions to the Review

A total of 385 written submissions were sent to the review by the end of September 2006. 212 items (55%) were from ILF users and their families. Many of these people requested anonymity and therefore we do not identify any of the individual submissions here. Thirty three submissions (8.6%) were sent by people working in social care responding in a personal capacity. We also respect that many of these submissions were sent in confidence and we also do not identify any of these. However, we are most grateful to all those concerned who sent us considered and very helpful written responses.

The remainder of the submissions (140 items, 36.4%) were from local authorities, a few NHS Trusts and a wide range of other organisations. Some of these were brief acknowledgements of the review taking place (which are not listed), while others were more extensive written documents. All of the responding organisations are listed below.

Local Authority, Care Trust and NHS Trust Responses

Angus Council
Bath and NE Somerset Council
Birmingham City Council
Bury Council
Cambridgeshire County Council
Carmarthenshire Council
Cheshire County Council
Conwy County Borough Council
Cornwall County Council
Coventry City Council
Cumbria County Council
Denbighshire County Council
Derby City Council

Doncaster Metropolitan Borough Council
Dudley Metropolitan Borough Council
Dundee City Council
East Ayrshire Council
East Lothian Council
Eastern Health and Social Services Board, Belfast
Edinburgh City Council
Essex County Council
Falkirk Council
Flintshire County Council
Gateshead Council
Glasgow City Council
Gloucestershire County Council
Hartlepool Borough Council
Hertfordshire County Council
Hull City Council
Inverclyde Council
Isle of Wight Social Services
Kent County Council
Knowsley Metropolitan Borough Council
Lancashire County Council
Leeds City Council
Leicester City Council
Leicestershire County Council
Lincolnshire County Council
London Borough of Barking and Dagenham
London Borough of Barnet
London Borough of Brent
London Borough of Hammersmith and Fulham
London Borough of Islington
London Borough of Sutton
Medway Council
Middlesbrough Council
Newport City Council
North Somerset Council
Northern Health and Social Services Board, N Ireland
Orkney Council
Peterborough Primary Care Trust
Rotherham Metropolitan Borough Council
Sheffield City Council
Solihull Care Trust
Southampton, Learning Disability Services
Suffolk County Council
Sunderland City Council
Swansea City Council
Swindon Borough Council
Tameside Metropolitan Borough Council
Torbay Care Trust
Torfaen County Borough Council
Wakefield Metropolitan District Council

Warrington Borough Council
West Lothian Council
West Sussex County Council
Westminster City Council
Wigan Metropolitan Borough Council
Wirral Metropolitan Borough Council
Worcestershire County Council

Organisational Responses

Age Concern England
Belfast Centre for Independent Living
Brain Injury Rehabilitation Trust
Centre for Independent Living, Belfast
Contact a Family
Council of Disabled People Warwickshire and Coventry
Direct Payment Support Providers Network
Disability Alliance
Disability Cornwall
East Anglian ILF Contact Officers Group
East Living
Eastern Region Independent Living Fund Contact Officers
Enable Enterprises
Equalities National Council
Foundation for People with Learning Disabilities
GAD Organisation
Hammersmith and Fulham Action on Disability
Hampshire Centre for Independent Living
Herefordshire Centre of Independent Living
IAS Services
ILF
In Control
Independent Living Alternatives
Inverclyde Centre for Independent Living
Leonard Cheshire Foundation
London Direct Payments Forum
Lothian Centre for Integrated Living
Mind
National Autistic Society
NCIL
PAMIS – in Partnership with People with Profound Learning Disabilities and their carers
Public and Commercial Services Union
Penderels Trust
Physical and Sensory Impairment - Wakefield District
Royal National Institute of the Blind (RNIB)
SCOPE
Scottish ADSW Direct Payments Network
Scottish Personal Assistant Employers Network
Spinal Injuries Association

Sunderland Carers Centre
The Action Group
The Shaw Trust
United Response
Voluntary Action Leeds - PSI Network
Wakefield District Physical and Sensory Impairment Group
WECIL Ltd (West of England Centre for Inclusive Living)

Consultation Meetings

Six consultation meetings took place during August and September 2006. These were held in: Newport; London; Belfast; Leeds; Edinburgh and Birmingham. A summary report is attached as Appendix 2.

Interview Programme

Interviews took place with the following:

Louis Appleby	National Director, Mental Health, Department of Health
David Behan	Director General of Social Care, Department of Health
Bruce Calderwood	Director, ODI
Dame Jane Campbell	Independent Living Review
Margaret Cooper	Chair, ILF
John Crook and Helen Steele	Older People and Disability Division, Department of Health
Simon Duffy	National Director, In Control
Sharon Foster-King	Independent Living Funds, Motability and Vaccine Damage Payments, DWP
Rob Greig	National Director, Learning Disabilities, Department of Health
Gillian Harris	DWP Solicitor
John Hughes	DWP
Jacinda Humphry	Assistant Director, ODI
Ivan Lewis MP	Junior Minister, DH
Paul McCourt	Individual Budgets, ODI
Anne McDonald	Older People and Disability Division, Department of Health
Anne McGuire MP	Minister of State for Disabled People, DWP
Elaine Morton	Chief Executive, ILF
Martin Routledge and Zoe Porter	CSIP
Dr Jenny Morris	Independent Living Review
Janet Walden	Individual Budgets, Department of Health
Patience Wilson	Programme Head, Independent Living, Department of Health

In addition, informal discussions took place with:

Caroline Glendinning (Individual Budgets evaluation team)

Gerald Wistow (Individual Budgets evaluation team).

Talking to people who use the ILF: Feedback from 6 consultation events organised as part of an independent review of the Independent Living Funds

During August and September 2006 we held six meetings around the different parts of the United Kingdom. These took place in: Newport; London; Belfast; Leeds; Edinburgh, and Birmingham. In total we met with more than 120 people with personal experience of using the ILFs (either as ILF users themselves, or as people with a family member who used the ILF). In some of the meetings there were also one or two people from local authority social services, from other service providers, and from organisations representing disabled people.

The consultation meetings were an important part of the review of the Independent Living Funds. We are very grateful to everyone who took part in the meetings. In addition to these meetings we have received a large number of written documents, and we have also undertaken a programme of one to one interviews.

The purpose of the review of the ILF is summarised in Box 1 opposite.

We listened to what people had to say at the meetings and we wrote this down on flip charts. We know that many people who attended the events will want to know what was said at the other meetings. We decided to write this brief summary to reflect the key themes and issues that arose across the six meetings. This will not always capture the detail of every meeting, but we believe we have identified the issues which were most prominent across the meetings. We are sending a copy of this to everyone who

participated in the meetings (and to those people who had indicated that they would attend but were unable to do so on the day). We will also be sharing this note with other people who might be interested in the views of ILF users.

Box 1 **The ILF Review**

The Department for Work and Pensions (DWP) commissioned independent consultants Melanie Henwood and Bob Hudson to carry out a review of the Independent Living Funds.

The review is considering:

- Whether the ILF is the best way of providing support.
- If not, whether a different model is required.
- What – if any – changes might be needed to improve the way the ILF operates.

What do you think about the ILF?

At the beginning of each meeting we told everybody that there were 'no wrong answers'. We wanted people to be able to tell us what they thought, and what their experiences of using the ILF are like, without worrying that they were going to say something wrong. People were very honest with us and were very helpful in identifying both what is good about the ILF, but also where things could be better.

In many ways the six meetings identified very similar issues. But the meetings were also different in their own ways, and there was something new wherever we went. The fact that many issues were identified repeatedly suggests that these findings may be seen as fairly typical of the experiences of using the ILFs.

The Good News

We began by asking people at each meeting to tell us what is good about the ILF and to explain how it helps them. Lots of positive features were identified. In looking at the lists from each meeting we have been able to group these under some key headings. These can be viewed in terms of two main categories. First are the features which relate specifically to the value of the ILF in people's lives. Second are the features which are valued in the way that the ILF is organised and operates.

The importance of the ILF

- Support in living your life.
- Choice and control.
- Support for the whole family.
- Flexible support.
- Enabling people to remain independent.

In all the meetings people were enthusiastic and positive in emphasising the importance of the ILF in their lives. The following quotes are typical of many comments that were made:

“The ILF means I can get my life back.”

“I wouldn't know what to do without the ILF.”

“The ILF allows you to live the life you want.”

“Before ILF I was treated like a child; now I am treated like an adult.”

Many people emphasised the importance of the ILF in providing support to the whole family. In particular, people valued the fact that using the ILF meant that they did not have to rely so heavily on family (and friends) for help because they were able to pay care workers and personal assistants (PAs) to help them.

From the point of view of family members and carers, knowing that a person was getting support or being able to get out and about to do what they wanted, provided reassurance. It also relieved them of some pressure, and while most family members want to be involved in supporting others, many recognised that being able to delegate some of the responsibility made a big difference to their own lives.

Having choice and control over the type of support that is provided, and who provides it (and when), are major benefits of the ILF which were widely identified. The ILF funding enables people to organise the services and support that they want and to fine tune it to their needs. This was frequently contrasted with the ‘take it or leave it’ experience which many people had of using local authority social services where there was little choice.

Support in living a life is clearly about much more than simply getting help with care needs. Many people told us about the way in which the one to one support they could buy using the ILF enabled them to do things and go to places (such as going to work, or to the pub, church, shopping, or to watch football), which they would otherwise not be able to do.

Not surprisingly, given the high value that people attach to the ILF, many comments emphasised that they would be “lost without the ILF.”

Organisation and Operation of ILF

The way in which the ILF is organised and operates was also frequently identified as a positive experience. In particular:

- Good assessment processes.
- Flexibility in how money can be used.
- Continuity of contact with ILF.
- You are trusted to get on with it with little interference.
- ILF puts pressure on social services to do their part.
- National system which is portable if you move.

The positive experiences of ILF assessment were identified by most people in all of the consultation meetings. ILF assessors were seen as knowledgeable, friendly and helpful people who approached the assessment as a two-way discussion and who went out of their way to be helpful and to try to ensure that all needs were taken into account. Many people contrasted this with their experience of assessment from social services (described as “chalk and cheese”). While the ILF assessors were seen as working on the side of service users, social services assessments were often experienced as restrictive with assessors trying to limit what support or funding people would be given.

Once people have been allocated ILF support, reviews are infrequent

(typically every two years), unless circumstances change and people need to have a review sooner. This was generally viewed very positively and ILF users valued the fact that they were not constantly being revisited. At the same time, when reviews do take place, it usually involves the same assessor and this continuity and familiarity was seen as particularly important. Many people remarked that they could always contact the ILF if they needed to and could talk to someone who would know about their circumstances and who would remember them. This was not the experience of everybody, as we shall explore below.

While local authorities operate their own eligibility criteria for social care, which can vary significantly between authorities, the ILF is a single national system. If people move to a different area, there is no danger that they will no longer meet the criteria for the ILF.

As we will see later in this report, the partnership between the ILF and local authorities can sometimes be problematic. However, it was also clear that the need for local authorities to provide £200 a week worth of services or Direct Payments for people using the ILF could provide a way for pressure to be exerted on local authorities to ensure they met their share of commitments.

ILF funding is provided directly to people who meet the eligibility criteria; unlike Direct Payments it is not administered via local authorities. This direct relationship with the ILF was highly valued and it was also viewed as efficient in reducing unnecessary bureaucracy and administration.

People generally found that the monitoring requirements in accounting for how ILF is spent were easy to

manage (and less demanding than those required by Direct Payments). As one person remarked to us, “you are not cross-questioned by the ILF about how you spend the money.”

The Bad News

It would be surprising if there were no problems at all in people’s experiences with the ILF. In all of the meetings, once people had told us how important the ILF is in their lives and how they value it, they also went on to identify various frustrations and concerns. These were mostly around the following themes:

- Slow application process.
- Restrictions in what ILF money can be used for.
- Restrictions in who can be paid by ILF.
- ILF payment rates.
- Support with managing ILF.
- ILF eligibility criteria.
- Means testing and financial contributions.
- Lack of cash flow roll-over.
- Payment in arrears.
- Annual up-rating.
- Poor awareness of ILF.
- Poor transparency and accountability of ILF.
- Partnership with local authorities.

In several meetings people commented on the slowness of the initial process in applying to the ILF. There could be considerable delays between contacting the ILF, having the

assessment conducted and receiving any payment.

Before anyone can apply to the ILF, they have to know that it exists. A recurrent theme in all of the meetings was that the ILF is one of the ‘best kept secrets’ and that getting to know about it often depends on pure chance, or on being told about it by other service users. Local authorities, and different social workers, vary in their knowledge of the ILF and in the extent to which they actively encourage people to apply for it. There is no automatic process for ensuring that people who could be eligible are told about the ILF or helped to apply for it. Potentially there are many more people who could benefit from the ILF who have no knowledge of it.

Despite all of the positive features about the flexibility in how people can use ILF funding, there are also difficulties in staying within the rules. In particular, ILF is intended to pay for ‘personal care and domestic assistance’. This can exclude certain types of support which people need in living their lives (such as around leisure opportunities). This is a major frustration for many ILF users. Unusually, this is an area where ILF is compared much less favourably with Direct Payments which many people experience as more flexible.

Restrictions on the use of the ILF can limit the activities that people participate in, and it was remarked that the ILF only “covers the bare bones” of support needs. For example, if a person wishes to go horse riding, or swimming, or to the cinema, but they need assistance to do so, the ILF will pay for the support that the person needs in doing the activity. However, it will not pay for the costs of the PA in taking part in the activity. This will mean that the ILF user must pay for

the PA if they want them to accompany them (but they cannot be recompensed for this from the ILF). Perhaps the most striking area where this limitation is experienced is around holidays. While the ILF will pay for the support that a person needs if they go on holiday (just as they would receive if at home), the actual costs of taking a PA on holiday with them has to be carried by the ILF user themselves who will have to pay for both holidays.

We were also told that that ILF does not permit holidays to be taken outside of the UK (or for people to employ PAs in another country), and this was also seen as an unnecessary restriction.

The fact that relatives cannot be paid for help they provide if they are resident in the same household is a controversial issue. Some service users would definitely not want to employ relatives (or spouses) to care for them as they want to be able to keep their relationships on a personal basis. On the other hand, many people commented to us that family members will provide care in any event, and they feel it is exploiting good will not to be able to pay them for this help.

One area of difficulty which was highlighted in all of our discussions concerned the need for support in managing the ILF. Some users of the ILF take on the responsibilities of being the direct employer of PAs, while others pay an agency to manage this side of things on their behalf. Managing an ILF budget and understanding the responsibilities of running a pay roll and associated tasks can be very demanding, particularly for people who may not have had previous business experience. Many ILF users told us how difficult it had been – especially when they were first

getting started – to understand what they had to do.

Some service users benefit from the support and advice offered by local Centres for Independent Living, or by other advocacy services, but not everyone has access to such support. People need training and support not only to understand the practicalities of keeping records and accounting processes, but also to understand what it means to be a good employer.

The amount that the ILF pays and the rates that it sets for paying PAs are widely seen as inadequate and can make it difficult for service users to be good employers. Many people recognised that their PAs do highly skilled work which is very poorly remunerated. This can cause problems both in attracting and retaining help and support.

The ILF does not pay a mileage allowance, which can be a particular consideration for service users who live in remote or rural areas. It was also pointed out that the ILF does not allow extra for weekends or bank holidays, although all staff agencies charge extra for supplying care staff at these times. The failure for ILF to be automatically uprated in line with inflation was also widely resented.

Other financial issues arise over the way that ILF money is paid 4 weeks in arrears (unlike Direct Payments which are paid in advance). This can cause hardship particularly in the start-up phase of using the ILF. Many people commented on the need to ‘double fund’ arrangements whenever they took on a new care worker or PA since there would need to be a transitional arrangement where they shadowed current staff and were trained. In effect the service user would need to pay double costs for this period in

order to ensure staff were able to assume the responsibilities of the job.

It was suggested on a number of occasions that it would be helpful if people were able to roll-over underspend throughout the year in order to establish a contingency fund which they could draw down if they needed additional resources.

Other frustrations were identified in the way that ILF funding would cease if someone was admitted to hospital. ILF users would often need to continue paying a retainer to staff to ensure their availability when they were discharged from hospital. Many people also commented that they still had personal care needs even when they were in hospital (since the health service rarely understood their needs or had suitably trained staff who could provide the support they needed), and ideally they needed to be able to continue to pay for personal care while they were in-patients.

The eligibility criteria for the ILF are viewed as complex and often unfair. The criteria are summarised in Box 2 below.

The need to receive £200 worth of support from social services was understood in terms of sharing the costs of care between local authorities and the ILF. However, in practice this can mean that people are obliged to use poor services (particularly day care) which they don't want and which they would not choose, but without which they would not qualify for the ILF. This arose as a particular issue during our consultation meeting in Northern Ireland where there was concern that the option of receiving a Direct Payment instead of services was not available and people were therefore obliged to use day care services they did not want.

Box 2 Eligibility criteria for the ILFs

In order to get help from the ILF a person must meet **all** of the following criteria:

- Get **at least £200 a week** worth of support from social services.
- Be **aged between 16 and under 66**.
- Receive the **higher rate of Disability Living Allowance (DLA)**.
- Be living in the UK and expect to continue living in your home for **6 months** after you have applied.
- Have **capital and savings of less than £18,500** (including the resources of your partner).

There are also wider issues which arise around the partnership with local authorities. In particular, where the ILF contribution needs to be matched £ for £ with local authority contributions people can become caught up in disputes ("in the middle of a three-way argument") and the unwillingness or inability of social services to increase their financial contribution to a package of support.

The age limits around applying to the ILF were generally seen as unfair, particularly in respect of older people. If someone is already receiving the ILF before they are aged 66 they can continue to receive it (so long as they satisfy all the other eligibility criteria), but they cannot apply to the ILF for the first time if they are 66 or older. People in the consultation meetings generally viewed this as wrong in principle, and disliked the assumption that once you reach a certain age your

rights to an independent life are more limited.

There was much discussion in all the meetings about what money is taken into account in assessing entitlement for ILF, and how people's financial contributions are determined. There are issues around both the principles and the practicalities involved.

The capital and savings limits were often questioned. Why the ILF cannot help people who have more than £18,500 in capital was challenged, particularly when a different capital limit is used in other calculations (such as people's contributions to residential care where the capital limit is £21,000). People also questioned why a partner's savings and capital are included in calculations.

Anyone who receives the ILF is also assessed to see how much of their own money they must contribute towards their care costs. Anyone entitled to ILF help will already be receiving the higher rate care component of Disability Living Allowance (DLA), and half of this benefit is taken into account as available income. People who receive Income Support may also receive the Severe Disability Premium (SDP). This benefit is paid to people in recognition of the extra costs associated with disability; the ILF expects all of SDP to be paid towards the costs of care. Other benefits and income are also taken into account (including any occupational pension). However, earned income is not taken into account.

Some ILF users feel strongly that if independent living is a right then it is wrong in principle that people should have to pay for the care they receive. Many service users were critical of DLA and SDP being taken into account

and resented having to pay the money over.

The upper limit to how much the ILF can pay to any person was often criticised. It was also often remarked that the £200 minimum threshold for the local authority contribution was too low and should be raised since some local authorities used it as a justification for providing only the minimum amount of £200 rather than anything extra that might be required.

The final set of issues that were identified as problematic (or potentially problematic) are those we have identified around transparency and accountability.

We have noted that most people's experience of contacting the ILF were positive. However, in all meetings some people reported less favourable experiences and described telephone calls with the ILF which were unhelpful, or where the ILF person was "curt" or ill-informed. In one meeting it was suggested that all ILF employees would benefit from disability awareness training.

In all the meetings there was very little awareness of how the ILF operates as an organisation. Indeed, it was remarked at times that the ILF is "shrouded in mystery." In particular, most people are unaware that the ILFs are administered by a Board of Trustees. Who the Trustees are was a matter of interest. Views were split on whether Trustees should be disabled people but in general it was believed that a majority of Trustees should themselves be disabled (and some people believed that this should be the case with all Trustees). Without personal experience most ILF users at the meetings did not believe that Trustees would understand the issues adequately.

There was some criticism about the lack of awareness about appeals procedures and concern that appeals to the ILF were not conducted in a transparent and open way that ILF users could have access to.

None of the ILF users who participated in the consultation meetings seemed to be aware of the existence of an ILF User Group. On learning of its existence people were keen to know more: how could they get their views known by the group? How did it operate? Why was there only one group? Why isn't there a regular system of local consultation? Why can't the group discuss matters of policy?

It was clear that the consultation meetings were the first opportunity that most ILF users had ever had to discuss their experiences. People generally seemed to find this a valuable experience and there is no shortage of interest in establishing regular consultative processes. However, people were clear that such processes should be genuinely consultative and not tokenistic. As one person remarked: "we want an alternative user group – not an ILF fan club."

Any Recommendations?

At each consultation meeting we asked people if they had any specific recommendations or ideas about how things should be changed to improve the ILF. Most of the changes that people would like to see related directly to the difficulties that have been identified above. However, there were some specific messages that recurred across the groups. In particular:

- People receiving higher rate DLA should automatically be given a leaflet about the ILF.
- The ILF money should not be integrated within local authority budgets.
- Assessment processes for social services, or Direct Payments and ILF should be integrated (but the ILF model should be the one that was adopted).
- A small contingency fund would allow short term changes in circumstances to be dealt with flexibly.
- The ILF needs to recognise the disability related costs of living, or else adopt fairer charging guidelines.
- The ILF needs to have regard to the different circumstances around the countries of the UK.
- ILF payments should not be limited to personal care and domestic assistance.
- There needs to be more support for users in finding, training and employing PAs.
- Index-linked increases in ILF rates should be made automatically.
- Reviews should be handled with greater speed.

We are extremely grateful to everyone who took part in our consultation meetings. The discussions will inform our review. We will be reporting to the DWP by the end of December and will finalise our conclusions and recommendations for the ILF by the end of January 2007.

Appendix 3: Glossary

AA	Attendance Allowance
BME	Black And Minority Ethnic
CAA	Constant Attendance Allowance
CILs	Centres for Independent Living
CSCI	Commission for Social Care Inspection
COGA	Conditions of Grant Agreement
CSIP	Care Services Improvement Partnership
DCLG	Department for Communities and Local Government
DDA	Disability Discrimination Act
DED	Disability Equality Duty
DFG	Disabled Facilities Grant
DH	Department of Health
DHSSPS	Department of Health, Social Services and Public Safety
DIG	Disablement Income Group
DLA	Disability Living Allowance
DP	Direct Payment
DWP	Department for Work and Pensions
FACS	Fair Access to Care
GCIL	Glasgow Centre for Inclusive Living
GSCC	General Social Care Council
HRDLA	Higher Rate Disability Living Allowance
IBSEN	Individual Budgets Evaluation Network
IB	Individual Budget
IC	In Control
ILF	Independent Living Fund
ILFAs	Independent Living Fund Assessors
ILT	Independent Living Transfer
LA	Local Authority
MRDLA	Medium Rate Disability Living Allowance
NCIL	National Centre for Independent Living
NDPB	Non-Departmental Public Bodies

NHS	National Health Service
ODI	Office for Disability Issues
ODPM	Office of the Deputy Prime Minister
OPCS	Office of Population Censuses and Surveys
PA	Personal Assistant
PCDA	Personal Care and Domestic Assistance
RAS	Resource Allocation System
SAP	Single Assessment Process
SCIE	Social Care Institute for Excellence
SDP	Severe Disability Premium
SE	Scottish Executive
SPAEN	Scottish Personal Assistant Employers Network