



Department  
for Work &  
Pensions



# Independent Living Fund

Post-closure Review

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January 2017

Research Report No 934

A report of research carried out by NatCen on behalf of the Department for Work and Pensions

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# Summary

The Independent Living Fund (ILF) was set up in 1988 to provide financial support to disabled people with high support needs. It was permanently closed in June 2015 and the responsibility for supporting ILF recipients in England was passed to local authorities (LAs). The aim of the study was to provide a qualitative assessment of the experiences of the closure in England, as perceived by former recipients and LA staff.

Former recipient views and experiences of the ILF closure ultimately hinged on their new arrangements under the LA. Those that were awarded improved, matched, or a small reduction in their care and support package had maintained the level of support and care they received prior to the closure, as well as a similar level of choice and control over their care. They also reported limited or no changes to their independence.

Those with a heavily reduced award experienced multiple changes as a result. They argued that reductions in care were unfair and denied them opportunities to participate fully in society. They encountered changes and restrictions to daily activities, including less support for engaging in leisure activities, work and volunteering. LAs found that face-to-face meetings with former recipients and their next of kin to sensitively discuss alternative provisions, changes and reductions to care, helped to mediate these difficult decisions.

It was the period of the uncertainty about whether the ILF would close that generated fear and anxiety among former recipients, which continued until they were notified of their new arrangements. Anxieties centred on what the new LA arrangements would be and whether all their care needs would be met. The ILF closure brought about wider concerns about the social care system, regardless of the new arrangements, and was felt even by those with improved and matched packages. Former recipients felt vulnerable to future reductions to funded care and support.

While ILF communications about the closure were reported to be clear and frequent, satisfaction with LA communications varied. Former recipients experienced different transitional journeys dependent on the approach taken by their LA. LAs that appointed a dedicated delivery team facilitated a smooth transition. Inclusion of project staff with prior knowledge of the ILF aided their understanding of the potential sensitivities involved in the transition. Collaborative working with the ILF was felt to provide LAs with a better understanding of former recipient needs.

The findings suggest that poor experiences of the transition in particular LAs could have potentially been improved by better communications about how and when the new arrangements would be decided. Future anxiety related to annual reassessments might likewise be mitigated by similar improvements. Having high quality staff that were experienced and showed sensitivity about an individual's circumstances facilitated a positive transition journey. The smooth monetary transfer was considered a successful aspect of the transition. However, LA staff suggested that a concrete measure of success of the transition would be gained at the next scheduled care reviews.

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Finally, a special thank you to Hayley Lepps who was central to the set-up of this project and delivering a number of the interviews.



# List of abbreviations

<b>CC</b>	County Council
<b>DBS</b>	Disclosure Barring Service
<b>DWP</b>	Department for Work and Pensions
<b>ILF</b>	The Independent Living Fund
<b>LA</b>	Local authority
<b>NHS CHC</b>	NHS Continuing Healthcare
<b>PSED</b>	Public Sector Equality Duty
<b>REC</b>	Research Ethics Committee

# Glossary of terms

<b>Care Act 2014</b>	In April 2015, the Care Act 2014 replaced most previous law regarding carers and people being cared for. It outlines the way in which LAs should carry out carer's assessments and needs assessments; determine who is eligible for support; charge for both residential care and community care; and places new obligations on local authorities. The Act is mainly for adults in need of care and support and their adult carers. <sup>1</sup>
<b>Care and support package</b>	A combination of services to meet a person's assessed needs as part of the care plan arising from an assessment or a review.  Care and support describes the help adults with needs receive to meet activities fundamental to functioning, e.g. personal care and mobility about the home. As well as activities that are important aspects of living independently, e.g. personal assistants and day services.
<b>Direct payments</b>	Direct payments are intended to provide independence, choice and control by enabling people to commission their own care and support to meet their needs. Cash payments provided by the LA to individuals who meet the conditions, to give the person control over how money is spent to meet their needs.
<b>Family carer</b>	Members of former recipients' families providing unpaid care.
<b>Formal carer/paid carer</b>	A paid carer either self-employed or employed through an agency providing care to former recipients. Funding for carers could be provided by formal statutory sources (such as the local authority) or self-funded (by the care recipient or their family).
<b>Former recipients</b>	People who received funding from the ILF.

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<sup>1</sup> <https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/care-act-faq>

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<b>Group 1 and Group 2 ILF users/recipients</b>	<p>Group 1 users were clients of the original ILF which ran from 1988 to March 1993. Receipt of local authority (LA) funding was not part of the ILF and some Group 1 recipients were therefore unknown to their LA social services department.</p> <p>Group 2 users applied between April 1993 and July 2010. They were required to have a minimum LA contribution as part of their eligibility for the ILF.</p>
<b>Health and social care professionals</b>	<p>For the purposes of this report this term refers in the main part to social workers, and care providers, however, it can also be extended to doctors, nurses, occupational therapists, opticians, osteopaths, pharmacists, physiotherapists, etc.</p>
<b>Independent Living Fund (ILF)</b>	<p>A UK-wide scheme set up in 1988 to provide financial support to disabled people with high support needs and enable individuals to live independently. Recipients predominantly used funding received from the Independent Living Fund (ILF) to employ a personal assistant or a carer. ILF was permanently closed on 30 June 2015.</p>
<b>ILF case workers</b>	<p>Social workers employed by ILF to take on the cases of ILF recipients and provide them with advocacy, information or other services.</p>
<b>New arrangements</b>	<p>Former recipient's local care and support funded by the LA in place of ILF support. For the purpose of this report the new arrangements have been grouped into three categories: an improved, matched or reduced package of care compared with the arrangements under the ILF.</p>
<b>NHS Continuing Health Care</b>	<p>A package of health and social care funding, also known as CHC funding. It is provided to meet the cost of an individual's care in full because their primary need for care is a health need. It is not means tested and it is irrelevant what assets the individual has. The test applied is whether an individual's needs are sufficiently complex to rule that their needs are primarily a health and not a social need.</p>
<b>Proxy interview</b>	<p>An interview with a family carer on behalf of a former recipient whose health needs meant they were unable to take part themselves (e.g. the former recipient was non-verbal or did not have the cognitive ability to participate in a qualitative interview).</p>

## **Independent Living Fund – Post-closure Review**

### **Unscheduled care review**

Under the Care Act 2014 LAs have a statutory obligation to schedule an annual review of the care needs of the people they support. Changes in recipients' health conditions or wider circumstances may prompt a need for an unscheduled review within a 12-month period.

# Executive summary

## Background

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

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

## Study aims

The aim of the study was to provide a qualitative assessment of the experiences of the closure of the ILF in England, as perceived by its former recipients and LA staff within adult social services departments. This research does not provide a formal impact assessment, but ascertained the views of former ILF recipients and other stakeholders as to the implications of the closure (Section 1.2).

## Methods

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

- 50 former recipients of the ILF, or unpaid family carers that took part in proxy interviews on behalf of a former recipient who was unable to take part themselves due to the nature of their health condition; and
- staff working in ten different County Council or LA adult social care services divisions with responsibility for managing the ILF closure locally.

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

## **Local authority management of the transition (Chapter 3)**

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

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

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

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

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

## **Former recipient views and experiences of the transition (Chapter 4)**

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

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

### **Former recipient views and experiences of the new arrangements (Chapter 5)**

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

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

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

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

## **Independent Living Fund – Post-closure Review**

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



# 1 Introduction

## 1.1 The Independent Living Fund

The Independent Living Fund (ILF) was a UK-wide scheme established in 1988 to provide financial support to disabled people with high support needs. The fund was designed to enable individuals to live independently rather than in residential care. Recipients predominantly used funding received from the ILF to employ a personal assistant or a carer. The ILF was sponsored by funding from the Department for Work and Pensions (DWP). Although it was government funded, it was a non-departmental public body which operated as an independent and discretionary Trust Fund.

Some 20 years after its inception, the Government felt that it was no longer the right approach to provide funding for one section of the disabled population through an independent fund, as opposed to via the mainstream adult social care system. Significant changes to the social care landscape over the period were felt to have created a mainstream system which now provided the choice and control to disabled people over how their care and support is managed; choice which had been lacking within the social care system when the ILF was first introduced.<sup>2</sup>

A series of policy documents and legislation enacted by a number of governments moved incrementally towards what would now be recognisable as the current localisation and personalisation agendas. Developments of note include: the 1990 NHS Community Care Act which introduced a new entitlement for service users to a Community Care needs assessment, the responsibility for which lay with local authorities (LAs); and the 1996 Community Care (Direct Payments) Act, which granted LAs the power to direct payments to an increasing range of service users. The 2001 Health and Social Care Act extended this power to a legal duty for English LAs to offer a direct payment to anyone eligible for community care services. Personal budgets began to be developed from 2003 within the existing legislative framework, becoming a significant part of the wider personalisation agenda from 2007.

There were also felt to be disparities within the ILF. There were known geographical variations in eligibility, LA involvement with the Fund<sup>3</sup>, and differences between eligibility

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<sup>2</sup> A statement by the Rt Hon Mike Penning MP, Minister of State for Disabled People, on the future of the Independent Living Fund, 6 March 2014. Available at: <https://www.gov.uk/government/speeches/statement-on-the-future-of-the-independent-living-fund>. Last accessed on 14 October 2016.

<sup>3</sup> Closure of the Independent Living Fund (ILF) Department for Work and Pensions, 6th March 2014. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/287236/closure-of-ilf-equality-analysis.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/287236/closure-of-ilf-equality-analysis.pdf) last accessed 14th October 2016.

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requirements of Group 1 and Group 2 users.<sup>4</sup> The ILF had also been closed to new applicants from 2010. Thus the decision was taken to close the ILF and to transfer responsibility for support provision to ILF recipients to LAs in England and the devolved administrations in Scotland and Wales. The decision regarding closure was announced in December 2012, and a date of March 2015 was set for the handover of responsibilities from the ILF to LAs and the devolved administrations.

Despite a government consultation on the closure, anxiety amongst some ILF recipients regarding the future of their care prompted a judicial review. In November 2013 the Court of Appeal overturned the Government's decision, ruling that the Government had not fully discharged its responsibilities required by the Public Sector Equality Duty (PSED), under the Equality Act 2010.<sup>5</sup> Following a second equality analysis, the Government again reached a decision to close the ILF. The analysis was undertaken as the Care Bill (that was to become the 2014 Care Act) was making its way through parliament. The resulting Act was expected to give all users in England the right to a personal budget, and place a further duty on LAs to meet the assessed needs of people who moved into their area until they carried out a new assessment and put a new care package in place. The equality analysis recommended that transferring the responsibility to support ILF recipients to LAs would enable them to utilise all the available funding for adult social care to support disabled people '*in a more consistent, effective and equitable way, within a cohesive mainstream system*'. Furthermore, the analysis suggested the transfer would make the system simpler and more straightforward for those receiving local authority funding.<sup>6</sup>

From 1 July 2015, responsibility for supporting ILF users in England and Wales passed to LAs in line with their statutory responsibilities. In order to enable LAs to meet these responsibilities in a '*flexible and responsive way*' without creating more administrative labour, the transference of responsibility did not stipulate a national framework for LAs to follow nor were the funds ring-fenced. A different model was adopted in Scotland and Northern Ireland. The Scottish Government established the Independent Living Fund Scotland (ILF Scotland)<sup>7</sup> to administer ILF for existing recipients. ILF Scotland operates as a discretionary fund that provides financial awards to eligible individuals, in Scotland and Northern Ireland.

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<sup>4</sup> There were two distinct groups of ILF recipients. Group 1 users were clients of the original ILF, which ran from 1988 and closed on 31 March 1993; being in receipt of local authority (LA) funding was not part of the ILF eligibility criteria at this stage. Some Group 1 recipients were therefore unknown to their LA social services department. Group 2 users applied on, or after 1 April 1993 until July 2010 and were required to have a minimum LA contribution as part of their eligibility for ILF. These recipients were known to the LA as they were in receipt of statutory support.

<sup>5</sup> The full judgement is available at: <http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWCA/Civ/2013/1345.html&query=bracking&method=boolean>

<sup>6</sup> Closure of the Independent Living Fund (ILF) Department for Work and Pensions, 6 March 2014. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/287236/closure-of-ilf-equality-analysis.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/287236/closure-of-ilf-equality-analysis.pdf) last accessed 14 October 2016.

<sup>7</sup> More information available at: <http://ilf.scot/>

DWP committed to '*monitor the actual impact of the closure of the ILF on former users of the ILF*<sup>8</sup> as it is important to understand the experiences of ILF recipients as they transfer to LA funding. DWP commissioned this research to investigate what the effect of closing the ILF has been in England. In particular the research explores the care outcomes experienced by former ILF recipients and examines how appropriate current support processes are.

### 1.2 Study aims

The aim of the study was to provide a qualitative assessment of the experiences of the closure of the ILF, as perceived by its former recipients and LA staff. It is important to stress that the research does not provide a formal impact assessment, but ascertained the views of former ILF recipients and other stakeholders as to the implications of the closure. The research sought to explore the following areas:

- support outcomes available prior to and post-ILF closure, and how these compare;
- experiences of the delivery and perceptions of the standard of care post-ILF closure; and
- experiences of living independently post-ILF closure, and notably influence on wellbeing.

### 1.3 Report structure

The report is separated into six chapters. This initial introductory chapter is followed by five distinct areas of the research approach and findings:

- Chapter 2 – outlines the research methodology.
- Chapter 3 – details LA models for managing the transfer.
- Chapter 4 – focuses on the transition journeys as experienced by former ILF recipients.
- Chapter 5 – discusses the new LA arrangements and their implications for former recipients.
- Chapter 6 – provides an overall discussion of the research findings.

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<sup>8</sup> DWP, press release: Future of the independent living fund, 6 March 2014, available at: <https://www.gov.uk/government/news/future-of-the-independent-living-fund>

## 2 Research methodology

This chapter outlines the research design and methods used to capture information from local authority (LA) staff and former recipients about their experiences of the Independent Living Fund (ILF) closure.

### 2.1 Overview of the research design

The aim of the study was to provide a qualitative assessment of the ILF closure, as perceived by its former recipients and LA staff within adult social services departments.

Qualitative depth interviews were carried out with 50 former recipients or family carers and staff from ten LAs with a responsibility for managing the ILF closure locally.

### 2.2 Qualitative depth interviews

Depth interviews were conducted with former recipients, family carers of former recipients (who were unable to take part themselves) and professionals working in LA adult social care departments with a responsibility for managing the ILF closure locally. Depth interviews were used for this potentially sensitive research topic as it allowed for one-to-one discussions whereby participant's individual narratives, views and experiences of the ILF closure could be discussed in depth in a private and confidential setting. Furthermore, participants had greater control within depth interviews to cover topics of particular resonance to their unique and often complex lived experiences.

The research was made as accessible as possible. Former recipients and family carers were given the choice of a face-to-face or telephone interview. Interviews were carried out at a time and venue of the participant's choice by an experienced researcher and generally lasted one hour. Breaks were offered during the interview as required. LA staff interviews were conducted by phone and lasted between 30 minutes to one hour.

Interviews took place between August and September 2016 and were carried out by a team of seven researchers.

#### 2.2.1 Topic guides

Two topic guides were developed, one specifically for each participant group; former recipients (these guides were also used for proxy interviews with family members) and LA staff.

The former recipient topic guide broadly covered the following areas of discussion:

- Personal background, both under the ILF and post-closure: living arrangements, employment status and health condition.
- Provision of care and support under ILF: discussion of the range of support provision accessed when in receipt of ILF, types of support and settings, satisfaction with care, levels of control and flexibility, any unmet care needs and levels of independence.
- The ILF closure: communication of the closure and how they experienced the transition.

- Provision of care and support under the new LA arrangement: mapping changes in support and care, discussion of the range of support provision accessed, satisfaction with care, levels of control and flexibility, unmet care needs and levels of independence.
- Experience of the ILF closure: whether they felt affected by the closure, in what ways and whether there had been changes to levels of independence.

The LA staff topic guide broadly covered the following areas of discussion:

- Job role under the ILF and post-closure: responsibilities and involvement with ILF and/or disability support and services.
- How the transition was managed locally: communications, transition management, reassessments, new arrangements, feedback from former recipients and staff.
- Reflections on the ILF closure: what worked well, challenges, implications of the closure for LAs and former recipients.

A copy of each topic guide is provided in Appendix A.

### 2.2.2 Ethical considerations

Ethical approval was successfully sought from NatCen's Research Ethics Committee (REC) which complies with the requirements of the Economic and Social Research Council<sup>9</sup> and Government Social Research Unit Research Ethics Frameworks.<sup>10</sup>

#### Recruitment of study participants

The Department for Work and Pensions (DWP) supplied NatCen with a list of former ILF recipients that had opted in to being contacted about research regarding the ILF and its closure. Former ILF recipients living in England were then sent a letter by the DWP and NatCen informing them about this study, and were given the opportunity to opt-out. Former recipients could opt-out of the study by notifying the DWP or NatCen by email, freephone or by returning the opt-out letter in the freepost envelope provided.

Former recipients that had not opted out were then selected from across 30 different social services departments in England (mostly at the County Council (CC) level). These individuals were contacted by the NatCen Telephone Unit to participate in a short screening exercise informing them about the study, assessing their willingness to participate and checking whether they had any support needs; for example whether they would need a carer present to support their participation in an interview, or whether a family carer may need to take part on their behalf.

Relevant LA staff were identified and contacted by the DWP research team. An email was sent informing the LA about the study and requesting relevant and willing staff to register an interest in participating in the study with the DWP or NatCen.

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<sup>9</sup> <http://www.esrc.ac.uk/funding/guidance-for-applicants/research-ethics/>

<sup>10</sup> [http://www.civilservice.gov.uk/wp-content/uploads/2011/09/ethics\\_guidance\\_tcm6-5782.pdf](http://www.civilservice.gov.uk/wp-content/uploads/2011/09/ethics_guidance_tcm6-5782.pdf)

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All potential participants were sent a study information leaflet explaining the research and describing what participation would entail. A full explanation was also given to recruited participants, both in writing and verbally prior to an interview. This information included an overview of the topic areas likely to be discussed and explained the voluntary nature of participation, including the fact that participants could withdraw from the research at any time up until the point of analysis.

Participants were reassured about the confidential nature of taking part. It was emphasised that they would not be required to share any personal or sensitive information that they did not wish to. At the start of the interview, participants were informed of the NatCen disclosure policy; whereby researchers may breach participant confidentiality only if they believe the participant is at risk to themselves, or another person.

### **Informed consent**

Consent to take part in the research was sought prior to the start of the data collection encounter. Interviews were audio recorded so that an accurate record of the discussions was obtained. Permission to audio record the discussion was obtained prior to the start of the interview. If an individual did not want to be audio recorded, detailed notes were taken with the participant's permission. At the end of the interview, former recipients and family members were offered a leaflet of national support organisations.

### **Managing interviews**

The research team conducting the interviews were highly skilled and experienced qualitative researchers who had extensive experience in interviewing on sensitive topics. This enabled them to draw on their skills and experience to manage the interview pace and dynamic, being led by the participant as far as possible, and ensuring the wellbeing of the participant was always the priority. All researchers conducting the interviews had enhanced Disclosure Barring Service (DBS) clearance.

### **Data quality**

The project was carried out in accordance with data security standards as set out by ISO 20252<sup>11</sup>.

### **2.2.3 Sample**

Qualitative research seeks to provide explanations of attitudes or behaviours rather than quantify their prevalence within the population. It is neither necessary nor desirable for qualitative samples to be as large as survey samples, or to be statistically representative. Instead, in order to provide robust explanations from which wider inferences can be drawn and to generate conceptual frameworks applicable to the broader population, it is essential that qualitative samples are selected purposively to encompass the range and diversity present in the target population(s). The robustness of qualitative research and the ability to draw wider inference from qualitative studies are highly dependent on rigorous purposive sampling. This is the approach we took for the sampling for depth interviews with former recipients (proxy interviews with family carers), and for the sample of LA staff.

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<sup>11</sup> A quality management system which establishes the terms and definitions as well as the service requirements for organisations and professionals conducting market, opinion and social research.

The populations of interest were former ILF recipients (or family members taking part in a proxy interview on behalf of former recipients), and LA staff; specifically:

- Former ILF recipients, living in England, Group 1 or Group 2 ILF award;
- Proxy interviews whereby unpaid family carers participated on behalf of a former recipient that was unable to take part themselves due to their health condition (i.e. they were non-verbal or did not have the cognitive ability to participate in a qualitative interview); and
- Staff working in CC or LA adult social care services divisions.

A total of 60 interviews were conducted, comprising 50 interviews with former recipients or a family member, and ten interviews with LA staff. This qualitative fieldwork was carried out with individuals living across England.

We recruited to a purposive quota sample representative of the different characteristics evident among ILF recipients, as is typical within qualitative research sampling. The sample captured a diversity of views, experiences and circumstances among the population of interest.

The table below presents the sample profile characteristics of former recipients included in this study.

**Table 2.1 Sample profile of former recipients**

Area	Sampling information	Number achieved
	Geographic area/LA or CC adult social service	25 different areas across England
Group	Group 1	14
	Group 2	36
Gender	Male	20
	Female	30
Disability	Physical disability	39
	Learning disability	11
New LA arrangement	Improved package	2
	Matched package	35
	Reduced package	13
Interview type	Former recipient	15
	Paired – former recipient and family carer	17
	Family carer (Proxy)	18
Total number of interviews achieved		50

## 2.2.4 Limitations of the methodology

It is important to consider the limitations of the sample when reviewing the qualitative research findings.

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Firstly, our recruitment approach may not have reached people who may now be living in residential care settings. This presents a limitation to the study, as an aim of the review was to assess whether the closure affected levels of independence and support required to live in the community. With the exception of one former recipient that was now living in residential care, the rest of the sample was living in the community at the time of interview.

Secondly, we did not capture the views of former recipients that could not participate themselves and who did not have a family carer that could participate on their behalf. Arguably these may be a small, but particularly vulnerable, group during the ILF closure and reassessment process. However, we conducted proxy interviews with (unpaid) family carers to mitigate the risk of excluding former recipients that did not have the verbal or cognitive capacity to participate in their own right.

Thirdly, achieving interviews with LA staff in the same area as former recipient participants happened in six LAs, but was not possible across the sample. ILF recipient interviews were dispersed across 25 areas. Sample sizes of recipients in the matched LAs were small (approximately 1-3 recipients); as a result the data cannot be used to draw conclusions between local transition arrangements and how former recipients experienced these.

### 2.2.5 Analysis

Verbatim transcripts of all recorded discussions (or fieldwork notes) were used to manage and analyse the data using a Framework<sup>12</sup> approach. Framework is a thematic approach to analysing qualitative data which involves developing an analytical matrix framework following familiarisation with the interview data, with different column headings for the key themes identified and a row for each interview/participant. Data from each interview was summarised into the appropriate column heading to allow for the systematic comparison of themes between participants. This approach helped to reduce the large volumes of data obtained, whilst ensuring comprehensive analysis. It also facilitated systematic between-case (looking at what different participant groups – former recipients, family carers and LA staff) and within-case (looking at how an individual's views and experiences on one topic relate to their views on another) investigation of the data.

Through reviewing the summarised data, the full range of views and experiences described by participants were systematically analysed, and the accounts of different participants, or groups of participants, were compared and contrasted. The use of the Framework approach ensured that analysis was fully documented and conclusions could be clearly linked back to the original source data.

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<sup>12</sup> Ritchie, J., Lewis, J., McNaughton Nicholls, C., and Ormston, R. (2014). *Qualitative Research Practice*, Ch. 11. London: Sage.



### 3 Local authority transition management

As outlined in the introduction of this report (Section 1.1), from 1 July 2015, responsibility for supporting Independent Living Fund (ILF) users in England passed to local authorities (LAs) in line with their statutory responsibilities. To enable LAs to respond in a flexible and responsive way, the transference did not stipulate a national framework, nor was the funding ring-fenced. This chapter details the different models LAs adopted for managing the transfer. The chapter draws on interview data with staff working in County Council (CC) or LA adult social care services divisions with a responsibility for the local transition management.

#### Key findings

- A clear timeframe for the transition period helped LAs in managing the transition process. Appointing a dedicated delivery team seemed to facilitate a smooth transition. The inclusion of staff with prior knowledge of the ILF aided an understanding of the potential sensitivities involved.
- Personalised and sensitive LA communications appeared to be linked to alleviating the anxieties of former recipients' and their next of kin about the transition, LA initial letter communications that mentioned financial constraints of the LA and/or the possible reduction to care raised concerns.
- Collaborative working with the ILF was felt to provide LAs with a better understanding of former recipient needs. Partnership working tended to happen between LAs and local ILF teams with an existing relationship. New partnerships were difficult to forge during the short transition period.
- It may have been beneficial to have had a longer overlap period with the ILF or to have retained staff with ILF knowledge for an extended period to support queries following the permanent closure.
- LA staff noted that the ILF transition coincided with the introduction of the Care Act 2014; LA staff and decision makers were still becoming familiar with the new eligibility criteria. Another challenge was negotiating reductions to care. Face-to-face meetings with former recipients and their next of kin to sensitively discuss alternative provisions, changes and reductions to care helped to negotiate these difficult decisions.
- LA staff found it difficult to assess the overall success of the transition at the time of this research. The smooth money transfer was considered to be a success and was attributed to the clear timeframe and early discussions with LA finance and direct payments departments. Levels of complaints, appeals and unscheduled reviews were also used as interim measures of success. Staff suggested that a concrete measure of success would be gained at the next scheduled reviews.

### 3.1 Planning for the transition

Each LA or CC developed a local plan for the transition management unique to their area and circumstances. Interviews highlighted the shared aspects of the planning phase across LAs such as: developing a timeframe for delivery of the transition, identifying a project delivery team, liaising with wider LA departments and sharing learning with other LAs. The different stages of transition planning are outlined below.

#### 3.1.1 Timeframe for delivery

LA staff reported having a clear timeframe to deliver the changeover. Having a predetermined date for the ILF closure, which coincided with the commencement of LAs' responsibility for making payments, was key in their planning and management of local arrangements. The 15-month period between the announcement of the Government decision and the permanent closure of the ILF was stated to provide ample time to identify a suitable delivery approach (including plans for the monetary transfer) and project team; involve other relevant individuals and LA departments; and sufficient time to assess former recipients for eligible care needs.

In anticipation of the potential transference of responsibility, some LAs had started early planning up to a year before the ILF closure was formally announced. This internal preparation was usually developed by LA staff with a lead responsibility for the ILF (from this research it is not clear whether each LA had such an ILF lead). Advance planning involved closer working with local ILF teams to gain a better understanding of the ILF and how funds were awarded and used; for example, by delivering joint assessments. Such groundwork was stated to hold LAs in good stead for when the closure was announced and for the subsequent transition.

Although the timeframe was generally felt to be sufficient, there were LAs with outstanding caseloads at the time of interview (i.e. not all former recipients resident in the LA had undergone assessment). In these cases, LA staff reported that their LA had made a commitment to former recipients to maintain the same level of funding they had received under the ILF until a review was conducted. This research is unable to comment on whether all LAs took this maintained funding approach, or whether this was unique to those interviewed for this study.

#### 3.1.2 LA project teams

LAs appointed project teams to plan and deliver the transition. There were broadly two models for the organisation of teams: dedicated project teams and matrix teams.

Dedicated project teams were created specifically to deliver the local transition. These were generally small teams with a few staff that took ownership of all stages of the process. Staff were selected from the existing internal staff workforce, or recruited externally based on their prior expertise or knowledge of the ILF. For example, one approach was to recruit ILF staff to the local LA project team. This recruitment approach was expected to harness as much information as possible about the ILF to ensure a smooth transition for both the LA and former recipients. The appointment of project staff that were knowledgeable about the ILF and had existing relationships with local ILF staff and/or with former recipients was reported to facilitate a sensitive approach to the transition by both LA respondents and former recipients (Section 4.2.2.).

The driver of adopting this model was an acknowledgement at a senior level that the ILF transition was potentially contentious and needed to be delivered in a sensitive way. Having a dedicated team was hoped to provide a holistic approach and a consistent service for former recipients. Furthermore, LA staff recounted having to forward a business case for the value of a dedicated team which had to be approved by senior management.

*‘So our decision was made that we would keep this work as a separate piece of work from the ordinary day-to-day case management, because we were concerned about actually diluting the focus, the understanding of what the task is across a raft of practitioners throughout [the County Council]. So we actually took that decision to hold it centrally within a small team of people.’*

(Staff member)

A matrix project team was the alternative model whereby senior managers led the overall planning of the transition, but the delivery (in particular, the assessment of eligible needs) was delivered by a range of staff. For example, one approach was to split the delivery between learning disability and physical disability teams within the LA, reflecting existing organisational divisions within the local adult social care department. Within this model, social workers were selected to carry out assessments based on available resource rather than their prior knowledge of the ILF. Social workers’ time was not necessarily protected to deliver these assessments during the transition period. They may have had to manage their existing caseloads alongside this work, which presented a challenge to completing the assessments within the planned timeframe (i.e. by the time of the ILF closure). To mitigate the risks of increasing existing social workers’ workloads, one approach was to employ agency social workers to deliver the assessments. This presented its own challenges, such as a high turnover of staff which caused delays to the transition timetable. Agency staff may have also found this work challenging, due to their lack of familiarity with the ILF, local LA processes or due to the sensitive nature of this work. Additionally, the employment of replacement agency staff was reported to be resource intensive.

*‘... agency worker[s are] not necessarily going to be familiar with the Council’s computer system and its paperwork. So, they’ve had to go through a period of local induction and support and being set up to access our paperwork and that’s taken a bit of time ... it’s been a little frustrating ... we feel that we’ve got the right level of workers in and that they are settled and they know what they’re doing, next thing you know, we just get notice to say that they’re going ... if we’ve lost that resource, then it places pressures on the existing team.’*

(Staff member)

This indicates that engaging a small, dedicated team for the transition process, and selecting staff with knowledge and experience of the ILF facilitated greater engagement with the transition process and understanding of the potential sensitivities involved.

According to LA staff, both dedicated and matrix teams were reported to have achieved the overall aim. However, based on staff descriptions of the local transition, the dedicated project team model appeared to provide a more holistic approach and encountered fewer challenges. Conversely, the matrix team approach might have allowed more opportunities for inconsistent approaches between staff and teams working within the same LA.

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Based on the sample of LA staff that took part in this study, the number of ILF recipients within an LA, or the size of the LA did not appear to determine whether a dedicated or matrix project team was adopted. One possible explanation is that the decision reflected the wider management and organisational culture of the LA social care department.

### **3.1.3 Engagement with wider LA departments**

Following the establishment of a project team, engagement with other relevant internal LA departments was a crucial aspect of the process. Project teams liaised with relevant departments to notify them of the impending change, include them in the planning process and identifying their responsibilities to support a positive transition. Relevant teams included, but were not limited to:

- Direct payment and finance teams to ensure a smooth monetary transfer from ILF to LA payments for all recipients during the transition period;
- Welfare teams to check that former recipients were in receipt of entitled support;
- Enquiries and complaints teams to prepare for potential contact from former recipients about the transition and to ensure that queries were directed to the project team. Additionally, project teams liaised with LA legal teams to provide support with relevant issues as necessary;
- The wider LA adult social care workforce to inform all staff, including those not involved in the transition work, of the local plans for transition;
- Adult safeguarding teams to review individual cases that LA staff were particularly concerned about (Section 3.3.6).
- Business support staff to arrange meeting rooms and send letters to former recipients, etc. Securing good business support was reported to support the smooth running of the project and safeguard project staff time for the delivery of the transition.

The level and type of engagement with these wider teams varied across LAs and included both regular meetings and ad hoc arrangements. Regular joint meetings between the project team and all key decision makers within relevant teams were found to be helpful during the planning phase and initial rollout of the assessments. Once the transition was in process (i.e. assessments had started and were running smoothly) these meetings were no longer felt to be as necessary or not required as regularly. Alternatively, ad hoc meetings between the project team and a lead person from a relevant team could be useful for specific cases or issues. For example, LAs reported liaising with the LA legal team when an issue that required their support arose. From the interview data, there appeared to be no clear advantage of either approach, however it was reported that working in the same building as relevant departments made working together easier.

### **3.1.4 Sharing learning with different LAs**

LA staff noted that they found it helpful to share learning with other LAs about their approaches when the opportunity arose. These communications were not strategically planned, nor did they occur across all LAs. They transpired as a result of existing relationships with other LAs, or chance meetings. This finding suggests that a forum for sharing learning between LAs during the planning and delivery of the transition might have been beneficial and may have supported LAs in establishing their local arrangements.

## **3.2 Collaborative working with the ILF**

The ILF remained in existence for 15 months following the announcement of its closure. LAs therefore had the opportunity to collaborate with the central and local ILF teams during this period. Not all LAs had previously liaised with the ILF during its existence. Collaborative working between the LA and the ILF during the transition period appeared to replicate historic working relationships between them. Joint working took various forms, but was described as positive and supportive of a smooth transition, where it did occur.

### **3.2.1 Questions and queries about the ILF**

LAs appreciated having the aforementioned overlap period while the ILF remained in existence. During this time, ILF staff were available to respond to LA queries. Additionally, meetings hosted by the ILF about the closure were a good opportunity for LA staff to receive information, ask questions and also provided an opportunity to network with other LAs about their models for change management.

Once the ILF ceased, LAs reported that they did not know where to direct new and outstanding queries. For example, LAs reported that they were unclear about contractual obligations for personal assistants/carers who were previously funded under the ILF, but under the new LA arrangements would receive a reduced rate of pay, or be made redundant. As such, issues arose following the closure of the ILF where LA project staff felt left to make judgements drawing on internal legal teams. It may therefore have been beneficial to have had a longer overlap period with the ILF, or to have retained staff with ILF knowledge for an extended period in order to support LAs to respond to such queries.

### **3.2.2 Sharing data and care plans**

Receiving contact details of former recipients and final care plans from the ILF was reported to be timely, enabling early roll-out of needs assessments. Some LAs noted that they had to request this information more than once before receiving it and that the format in which contact details were provided was initially difficult to work with. However, these were not reported to be widespread challenges.

### **3.2.3 Joint assessments**

Joint assessments between an LA social worker and the ILF assessor were felt to provide LAs with a better understanding of former recipient needs. LA staff also believed this approach provided a familiar and reassuring assessment environment for former recipients and their next of kin. Joint assessments during the transfer tended to happen where such arrangements had also occurred historically during routine ILF reviews.

### **3.2.4 Attempts at collaborative working**

There were also reported attempts at collaborative working between the LA and ILF during the transition that did not materialise. For example, an LA offered hot desks to local ILF staff so that they could work onsite at the LA offices. The approach was devised in an effort to facilitate joined-up working during the transition, however, this offer was not taken up. There were also instances where the LA attempted to arrange joint assessments but due to a delay in scheduling assessments this was not possible.

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The interviews revealed that in the absence of a prior working relationship, meaningful joint working between the LA and the ILF was difficult to establish during the transition period. For example, in one LA, an LA social worker accompanied the ILF assessor at the final ILF review with the former recipients. Joint assessment had not previously occurred in this LA and therefore presented a new way of working. The LA social worker did not feel actively involved in the assessment process, and therefore felt that a joint approach was not useful.

### 3.3 Implementation process

This section outlines how LA plans for the transition were implemented, the aspects which worked well and the challenges encountered. The execution of LA communications with former recipients and the assessments are also described and summarised below.

#### 3.3.1 Communications with former recipients

The ILF was responsible for communications with former recipients about the closure of the fund and for seeking their consent to share their contact details and ILF care plans with LAs (as detailed in Chapter 4). While some LAs had had sight of ILF communications, others reported that they had not.

LAs were responsible for communicating local transition processes and what the new arrangements would be. LAs generally communicated the local process to former recipients by letter, while individual arrangements were communicated through personalised ways; either in face-to-face meetings or phone calls and subsequently confirmed in writing. There were also examples of wider engagement activities; for example, the use of local radio and public events aimed at sharing the local transition process/arrangements with former recipients and other interested parties, such as next of kin, carers groups and disability rights campaigners. LAs that experienced high levels of anxiety among former recipients and their next of kin in the form of phone calls and letters reported that they were typically responding to similar types of queries. On reflection, a learning point for one LA was that holding citizen's meetings might have been an efficient and proactive way to alleviate anxiety among former recipients and their next of kin.

#### Initial LA letter

LA communications, particularly the initial letter sent to former recipients, set the expectations of former recipients. These communications either provided reassurance about the process, or unintentionally heightened anxiety about it (evidenced by the scale of phone calls and queries such mail outs resulted in). The features of initial LA letters that were reassuring to former recipients, included:

- acknowledgment that the closure of the ILF and transition was a worrying time for former recipients and next of kin;
- providing a named contact and dedicated contact details to direct queries to, which was possible in LAs with fewer numbers of former recipients; and
- outlining the local process, the next steps former recipients could expect, and a timeframe for assessments and outcomes.

On the other hand, LA staff that reported that their initial letter to former recipients had an unintended consequence of heightening anxiety also discussed how the mail-out of the letter resulted in a high volume of phone calls. LA staff recounted how such communications attracted contact from former recipients and their next of kin, reporting concerns about the local transition. The features of initial LA letters that were felt to have worried people, included:

- The mention of austerity and financial constraints of the LA;
- Mentioning of potential outcomes, including the possible reduction to care and support packages; and
- Request for former recipient's bank details in the initial letter; prior to any telephone or face-to-face meetings with former recipients.

*'We compiled an introductory letter ... it resulted in a plethora of very anxious phone calls from the service users, all anxious that the Council's gonna get involved. They're coming out to see them and they're gonna take their money away. So, a lot of reassurance had to be given to them in phone calls that were made back to them.'*

(Staff member)

Based on LA staff accounts, personalised and sensitive communications appeared to be linked to managing and alleviating former recipients' and/or next of kin anxieties. For example, one LA lead within a dedicated transition team called all Group 1 former recipients (previously unknown to the LA) with the intention of introducing themselves as a dedicated worker, outlining the local process and alleviating concerns they may have about working with the LA. In this particular LA, this personalised communication approach was made possible by having only a small number of Group 1 cases and a dedicated staff member to deliver it. With an appropriate staff to caseload ratio, this approach might also have been possible in larger LAs with a large caseload.

### 3.3.2 Assessment process

Following the initial letter communication and allocation of cases to a LA social worker, the rollout of assessments started. The order in which LAs carried out assessments differed. Based on the interview data, there was no evidence to suggest one approach worked better over another. The following approaches were outlined in interviews:

- Group 1 ILF recipients prioritised as these were unknown to the LA; or
- those with large care and support packages or those who were considered unlikely to be matched under LA eligibility prioritised; or
- prioritising individuals that contacted the LA with a concern or query about the transition and appeared to be particularly anxious; or
- assessment roll-out by geographic regions of the LA, whereby areas were determined by existing regional divisions (they were not newly created for ILF transition management).

### 3.3.3 Assessment formats

LAs favoured a face-to-face assessment format and reported to have at least one face-to-face meeting with each former recipient. Alternative models stipulated at least two or three visits with each former recipient. Multiple assessment visits with former recipients were either linked to the level of complexity of an individual case, or were specified by the LA to ensure the assessment was thorough. Several visits were thought to allow time for the allocated social worker to build rapport, understand the needs of individuals and discuss all possible options available. They were considered particularly important for engaging former recipients and next of kin in difficult and sensitive discussions, such as alternative provisions in place of LA funded carers and personal assistants, and possible reductions to care and support packages.

It was acknowledged that multiple visits were resource intensive. However, the advantages from the LA perspective were stated to be a thorough assessment and a better quality service for former recipients, as well as facilitating greater job satisfaction for social workers. Former recipients may have appreciated this level of contact. However, it is also possible that they experienced these as prolonging the transition period and increasing the period of anxiety without an outcome (as discussed in more detail in Chapter 4).

### 3.3.4 Considerations during assessments

Assessments generally took a similar format across LAs. The overarching considerations in assessments were:

- Assessing eligible care needs. These were generally assessed under the Care Act (2014);
- Financial assessment to establish whether former recipients needed to contribute to the cost of their care. Such assessments also sought to ensure individuals were in receipt of welfare support entitlements. This was a particular priority for Group 1 ILF recipients that were not in contact with LA services prior to the closure. This process took two possible routes: firstly, prior to assessments the LA welfare team proactively contacted former recipients to check that they were in receipt of entitled welfare provision; or, social workers signposted former recipients and next of kin to welfare teams if they suspected that they could be entitled to additional support.
- Understanding former recipient and next of kin preferences for LA support and whether they would favour direct payments or commissioned services;
- Whether current housing and living arrangements were suitable, including the possible need for alternative provision, such as residential care;
- LAs also considered non-financial options; care and support options that were cost-neutral or presented potential saving for the LA. For example, eligibility for National Health Service (NHS) Continuing Healthcare to transfer funding of care and support fully to the NHS; unpaid family care; voluntary and free services; volunteering and employment opportunities; and applications for local grants.



### 3.3.5 Unexpected outcomes of assessments

The assessment process resulted in unexpected outcomes, as noted by LA staff. These included:

- Identification of double payments, or where ILF money was used to ‘top-up’ LA funded personal assistants or carers. Such discoveries typically resulted in reductions to funding. Although these changes were viewed as positive by LAs, former recipients with reduced funding for care and support encountered challenges as a result of such reductions, as discussed in Chapter 5 (Section 5.3.1).
- Excess money (unused funds) in accounts of ILF recipients. In these circumstances, LAs described a joint decision between the LA and former recipient to reduce the care package in acknowledgement that they did not require the full award that they had received under the ILF.
- The closure of the ILF enabled conversations and exploration of alternative options for former recipients. Such changes would not have been considered without such a major review of funding and care options. In some circumstances assessments facilitated what LA staff viewed as positive changes, such as former recipients participating in volunteering opportunities, in place of a carer visiting in the day.

### 3.3.6 Challenges of assessments

LA staff reported the challenges that they encountered during the assessment process. These issues centred on the transition period coinciding with the introduction of the new Care Act (2014); decisions to reduce care and support packages; and resistance to the changeover from some former recipients and their next of kin. Further information is provided below:

#### Introduction of the Care Act 2014

The Care Act 2014 came into effect at the same time as transition assessments were being undertaken. Staff were reported to still be in the process of familiarising themselves with this new Act and how to use the eligibility criteria it stipulated at the time of the transition assessments. In one LA, former recipients were assessed under the old criteria and then had to be reassessed under the Care Act criteria, which required additional work. LA staff also reported having to explain their decisions for care and support to decision panels that were themselves also in the process of becoming familiar with the Act and all of its components.

#### Reductions to care and support

Reductions in care packages required sensitive handling. ILF care and support packages were, in some cases, larger than individuals were entitled to under the LA arrangements and Care Act criteria. A challenge that LAs therefore faced was that former recipients were both used to, and dependent on, a higher level of care. In such circumstances, careful negotiation and full consideration of alternative provisions was said to be important, as was the involvement of the former recipient and next of kin in discussions about reductions and alternative provisions. Some LAs used the wellbeing principal in the Care Act (2014) to assist in providing a higher level of care than an individual might otherwise be entitled to. However, use of this principle was not discussed across all interviews, indicating that the Care Act and its eligibility criteria might have been interpreted in different ways across LAs.

### **Resistance from former recipients and next of kin**

LA staff reported a perceived opposition from some former recipients and next of kin during the transition. This took the form of withholding information, cancelling appointments, or next of kin who were present at assessments making social workers feel threatened or unsafe. This was generally reported in areas that also had a high volume of calls from former recipients and next of kin about the local transition process. Consequences of such perceived resistance included: delays to the transition timetable; outstanding assessments (at the time of this research); more resource required to rearrange appointments; allocating two social workers to deliver assessments where threats had been experienced; and high staff turnover.

LAs also discussed former recipients that did not engage with the assessment process in that they refused an assessment, or did not accept the new award. In these circumstances, LAs either referred these cases to LA safeguarding teams for review or alternatively awaited former recipients to re-establish contact with the LA. Similarly, Group 1 recipients that did not consent to the ILF sharing their contact details presented a safeguarding concern for some LAs. An alternative perspective of LAs' staff was that these individuals had exercised a personal choice which also offered cost savings for the LA.

### **3.4 LA perceptions of the measures of success**

When reflecting on the transition process and assessments in particular, LA staff found it difficult to assess the overall success of the transition due to the short timeframe between the transition and taking part in this research. While staff generally lacked confidence that the transition resulted in cost savings for the LA, they suggested other indicators of success. Firstly, the smooth money transfer was considered successful; a finding echoed by former recipients (section 5.2.2). LA staff had anticipated that there might be challenges related to this. However, LA staff reported a seamless transfer which they attributed to having a clear timescale and early discussions with internal teams with LA finance and direct payments departments. Secondly, LA staff identified possible indicators of success such as the number of complaints, appeals, and unscheduled reviews. However, concrete measures of success for former recipients were expected to be identified at their next review. It was expected that clarity would be gained at the next scheduled review about whether the new arrangements sufficiently meet former recipients' needs and whether there were any unintended consequences for former recipients or their next of kin.

## 4 Transition journeys

This chapter outlines the views and experiences of former Independent Living Fund (ILF) recipients on the closure of the fund and transition to local authority (LA) responsibility. It covers the communication participants received from the ILF and LAs about the closure; participants' reactions to the closure; and their experiences of LA reassessments. The chapter draws on interviews with former recipients and proxy interviews with family carers.

### Key findings

- Former recipients were, on the whole, positive about the communication they received from the ILF about the closure of the fund. ILF communications were clear and kept recipients well-informed.
- Participants felt a sense of loss about the closure of the fund; and there remained a general lack of clarity about why the ILF was closed.
- As each LA adopted a different approach, satisfaction with LA communications about local reassessment process and new arrangements varied. Following the announcement of the closure, former recipients were anxious to know what their new arrangements would be.
- The announcement of the ILF closure, coupled with a lack of information regarding the new arrangements under the LA, generated anxiety among former recipients. People's worry was compounded by the fact that the funding transferred to LAs was not ring-fenced. Concerns centred on the prospect of reductions or changes to care and support arrangements which would have direct implications to having their care needs met and their ability to engage in activities that they wanted to.
- Former recipients reported feeling reassured about assessments that included ILF involvement such as joint assessments with ILF assessors and LA social workers, or use of ILF care plans during LA assessments. ILF staff were generally seen as more experienced and understanding of recipient's needs, compared with LA social workers.

### 4.1 Finding out about the closure

Participants cited a range of ways they first heard about the closure of the ILF. These included either hearing about the closure from their ILF case worker (either in person or by phone); through ILF user group meetings; formal letters from the ILF; or through news reports. Participants recalled hearing about the closure as early as two years prior to the official closing date. Once the final decision was announced to permanently close the ILF, initial communications to recipients were handled by the ILF. However, this responsibility was subsequently handed over to LAs. This section will discuss participants' experiences of the communication they received from both the ILF and the LA.

#### 4.1.1 Communication from the ILF

On the whole, participants were positive about how the closure was communicated to them by the ILF itself. Participants reported feeling that they had been given sufficient notice and that the ILF shared new information as it became available. Participants commended the ILF for providing information letters about the closure in accessible formats; for example, one

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former recipient received their letter in braille. During the lead-up to the closure, participants also recalled the ILF providing newsletters about the court proceedings<sup>13</sup> prior to the official closure of the fund, which added to some participants' sense of feeling well-informed.

*'I was actually kept well informed, and I really appreciated that. It didn't ... softened the blow, but it just helped'*

(Former recipient)

The ILF communications provided sufficient information about the process leading up to the closure, but participants felt there was limited information about the post-closure arrangements. However, there was a sense of acceptance among some participants that communications from the ILF were as good as they could be.

*'whenever the ILF wrote, and they was really saying what they was doing, but couldn't help with what the local authority were doing, "cause nobody knew"'*

(Proxy interview with family carer)

The counter view to this was that the communication from the ILF was not felt to provide sufficient detail regarding the new funding arrangements, which was the main source of participants' anxiety about the closure. A reoccurring theme among participants was the lack of understanding about why the closure was going ahead. This remained unclear to some participants once the closure had happened.

### 4.1.2 Reactions to the closure

Participants mentioned attentively following the media coverage of the legal case taken to the Court of Appeal in 2013, which challenged an earlier decision to close the ILF (see Section 1.1 for more details), and feeling increasingly anxious about the final outcome. Once the closure of the ILF had been announced in 2014, participants reported feeling an overall sense of sadness and loss.

*'That was like running into a brick wall full pelt. It really shook me up'*

(Former recipient).

Some former recipients recounted taking part in public debates and campaign activities during the interim period before the closure of the ILF had been announced. The types of activities participants attended included LA-led public consultations (which were offered by some LAs but not all); disability rights groups; ILF committee meetings; or writing to an MP. Despite engagement in such activities, some participants described how these meetings and activities further heightened the anxiety they felt about the closure. These forums did not provide reassurance as they did not tend to address their queries or concerns. Furthermore, those that participated in such engagement activities felt let down and not 'listened to' when the final decision was announced.

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<sup>13</sup> In November 2013, the Court of Appeal quashed the Government's decision to close the ILF and ruled that there had been a breach of the quality duties when making the decision to close the ILF. The full judgement is available at: <http://www.bailii.org/cgi-bin/markup.cgi?doc=ew/cases/EWCA/Civ/2013/1345.html&query=bracking&method=boolean>

*'I saw a lot of, you know, messages and written letters to MPs and all sorts, and then it still got closed, and I think that was quite disturbing, that nothing that people had said seemed to have been listened to ...'*

(Former recipient)

The confirmation of the closure raised a number of concerns among participants which centred on a potential loss of the ILF and the security they felt it provided them in meeting their care and support needs. Some former recipients mentioned feeling concerned about what the likely new arrangements would be, especially in the context of austerity. Participants felt particularly anxious about whether they would receive the same level of care; how they would cope with a reduced package; and whether they would be able to continue to live independently and maintain their usual daily activities which, for some, included work or volunteering.

There were some examples of former recipients so concerned about the closure and the prospect of losing some or all of their care that they became ill. For example, one former recipient disclosed that they were prescribed anti-depressants, which they attributed to the anxiety they felt in the lead up to the closure.

*'I got so worried about it, my nerves were so bad ... My consultants and the doctor, he's put me on what I call 'happy pills' now, but it's not working very well ... I'm still done in, I can't be cheerful about it.'*

(Former recipient)

This anxiety felt among participants was compounded by their confusion around whether LAs were ring-fencing the transferred funding, and the lack of clarification they received around this. Some participants mentioned feeling that it was 'wrong' not to ring-fence the funding, and wanted to know how this funding was now being used.

*'My main concern was the council didn't have this money ring-fenced for anything. So what happens if they're short of money? Will they stop our funding or what? That's the only thing that worries me.'*

(Proxy interview with family carer)

### 4.1.3 Communication from the ILF

Once the ILF had officially closed and the ILF had transferred people's details to LAs, LAs took over communication of the post-closure arrangements. LA communications were not mandated in recognition of the importance of localism. Therefore LA communications with former recipients were unique. The views and experiences of how and when LAs communicated local transition arrangements can be split into two broad types: those who were satisfied with LAs communications, and those who were dissatisfied. These are not objectively defined categories, but refer to how participants described their experiences of the communication they received.

### Satisfaction with LA communication

Participants that reported feeling satisfied with the communication their LA had provided felt that they received information about the process for reassessment and the outcome of any assessments in an acceptable timeframe.

*'We were all, you know, told in advance, really. Just before they started the ball rolling; they did tell us ... and tried to explain everything ... I'm not one for complaining, really. I was quite satisfied with everything.'*

(Proxy interview with family carer)

Being provided with enough time to process post-closure arrangements meant that participants could begin to organise their care and budget for any changes accordingly.

### Dissatisfaction with LA communication

Participants that felt LA communications were insufficient and/or unclear reported that their post-closure arrangements had been left undecided until the last minute, and that LAs and LA social workers were not able to provide them with the necessary information.

*'When you asked your social worker they said they don't know, "We'll wait and see", well we can't wait and see.'*

(Former recipient)

The lack of sufficient communication led to participants experiencing long periods of uncertainty which were described as stressful and damaging to their wellbeing. A widespread concern was that their funding would be reduced or cut completely, which would result in having unmet care needs and losing established carers.

*'... from the ILF we were sent a letter saying what was going to happen and the date this would finish ... and then we were told nothing, nothing at all from social services. In fact, when, at the end of the cut-off date, I didn't even know if I could still have my carers or how was I going to pay them. It was just horrendous.'*

(Proxy interview with family carer)

Former recipients cited wider implications of poor or slow LA communications. For example, participants recalled worrying that their carers may leave for more secure employment during the transition period. This was an eventuality for some participants and had severe implications on the former recipients and their families. For example, a family carer taking part in a proxy interview described how the protracted period of uncertainty led to a paid carer leaving for another job. This staff change was especially difficult for the former recipient with a learning disability to understand.

## 4.2 Transitions

### 4.2.1 ILF involvement in handovers to the LAs

The ILF put in place transfer arrangements prior to closure of the fund. These included a face-to-face meeting for all recipients with an ILF assessor where a support plan was developed detailing care and support needs. A social worker, or other LA representative, was invited to these meetings and recipients would receive a copy of their support plan following the meeting. Support plans were also passed on to LAs with the consent of recipients.<sup>14</sup>

#### Transfer of personal details

Although the transfer arrangements of the ILF were not systematically explored in interviews with former recipients, the automatic transfer of personal details was highlighted as being helpful by participants as it placed the responsibility of ensuring new arrangements were in place on LAs rather than on individual recipients.

*‘the ILF sort of made that passing easier for me, you know, rather than my having to go out and get in, you know, get in touch with people who I didn’t know who – who on earth I should be getting in touch with’*

(Former recipient)

#### Joint handover meetings

Those participants who mentioned having had a joint handover meeting with their ILF assessor and a representative from the LA were positive about it. Participants felt supported by their ILF assessor, who had often known them for a number of years, and who were able to advocate for them and clearly explain their care needs to the LA representative. Some participants felt that the presence of the ILF assessor at the joint handover meeting had either resulted in, or significantly strengthened their case for matched funding from the LA. The joint handover meetings were seen as more of a formality by former recipients who had already been informed by their LA that their funding would be matched for the first year, or until a full LA reassessment could be carried out.

However, participants also reported instances where they had been told that requests by ILF assessors for joint handover meetings had been declined by LAs, or where LA representatives had failed to attend scheduled meetings. In these cases former recipients felt let down by their LA.

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<sup>14</sup> The transfer of details to LAs required active consent by Group 1 recipients but happened automatically for Group 2 recipients who consented to sharing information with their LA at the application stage (see [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/439711/ilf-your-transfer-guide-england.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/439711/ilf-your-transfer-guide-england.pdf))

### Transfer of support plans

Participants who commented on the support plans developed with their ILF assessor viewed them as important as the ILF was perceived to understand recipients' needs better than the LA. However, it was not always felt that the LA had taken this information into consideration during their reviews. Some participants mentioned being informed by their LA that they had not received the support plan from the ILF.

### 4.2.2 LA assessments

All transition arrangements were made at a local level, thus the timing and requirements of LA assessments for former recipients varied from one LA to another. Former recipients stated that their LAs started their programme of reassessment prior to the closure of the fund, others immediately following closure, and others had a delayed programme of reassessments for up to a year after the closure. This meant that at the time of interview, participants were all at different stages of their transition journey. For example, some participants had been reassessed by their LA and had either accepted their new arrangement or were going through appeals and in some cases through legal processes to contest the outcome. However, others were in the process of being reassessed by their LA, and some participants were awaiting reassessment for their care to be funded through National Health Service (NHS) Continuing Healthcare.

Participant experiences of the reassessment process varied. Some participants described their transition journey as smooth and felt largely unaffected by LA reassessment, whereas others described the period of transition as acutely stressful and the reassessment process as taxing and detrimental to their wellbeing. As former recipients were at different stages of the transition journey, directly comparing and contrasting their experiences was not possible. Instead, common aspects of the reassessment process that were felt to be helpful or challenging by participants are presented below. Importantly, the extent to which these factors figured in individual transition journeys varied depending on what stage they were at, as well as the course their transition journey had taken.

### Helpful aspects

#### 'Good' social workers

Being supported by LA social workers was mentioned by some former recipients as positive and helpful during the reassessment process. Some described receiving help with filling in forms, whereas others described broader and ongoing support throughout the process from LA social workers. In these cases, LA social workers were perceived to be competent and working hard to ensure their care package would be matched, or in some cases, improved;

*'... I had a really good social worker that fought but I was trying to say, 'Oh don't worry about that because I just want to make sure I don't lose what I have now' ... But then she said, 'No, well, it's my job' so I don't really understand how she did it. But then I ended up with 24/7 care whereas before ILF shut, I didn't quite have 24/7'*

(Former recipient)



### **Challenging aspects**

The factors mentioned by former recipients as contributing negatively to the experience of the reassessment process included pressure on resources within LAs; a perceived lack of information about the reassessment process and alternative sources of funding; and a perceived lack of knowledge and sensitivity amongst LA social workers to carry out adequate assessments. Each of these factors is described in detail below.

### **Pressure on resources**

The general climate of budget cuts and austerity was described as an important factor contributing negatively to former recipients' experiences of the reassessment process. Former recipients linked feeling stressed and anxious to this perceived lack of resources and felt it substantially increased their sense of uncertainty regarding the outcome of their reassessment. Linked to this was a sense among some former recipients that in contrast to the ILF, that was seen to genuinely care about ensuring former recipients could live independently, the key priority for social services was to make cost savings. Social workers were perceived to be acting as accountants, primarily 'looking to make cuts' and seeing care outcomes as secondary.

Importantly, the perceived lack of resources was not just about finances to provide care and support, but also extended to wider concerns about resourcing which made some participants question whether adequate assessments could be carried out. Participants also commented on their experiences of problems with high turnover of staff in social services. This resulted in their frustration at having to undergo additional reassessments due to files being lost, errors in the support plans produced, or social workers having moved on to new jobs. Furthermore, those who had experienced getting no support with filling in reassessment forms felt that this had added to the burden of reassessments.

### **Lack of information**

A lack of clarity about the number and format of reassessments was also noted as adding to former recipients' anxieties about the transition. Those that were being reassessed, or referred for reassessment for NHS Continuing Health Care (CHC) funding, described feeling initially apprehensive about the process, as they were unfamiliar with this funding stream and did not know how it might affect their care. This included concern about whether they would be able to use the same care agencies in the event of being awarded funding through NHS CHC.

### **Social worker knowledge and sensitivity**

Some former recipients were concerned that LA social workers did not have sufficient expertise to carry out fair reassessments. It should be noted that social workers were typically unknown to former recipients and their family prior to the assessment. They were perceived to lack understanding of complex disabilities and rare health conditions, as well as an understanding of former recipients' care history and particular needs. In contrast, former recipients had often known their ILF assessors for several years and felt confident that their conditions and needs were understood and would be met as a result. Former recipients described ILF assessors as professional, experienced and having detailed understanding of what it meant to live with a disability.

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*'You know, we always play down our disabilities, and, and what our needs are. But she [ILF assessor] saw through me, and she knew much more about me than I probably was admitting. However, she really was the most helpful, and I just wonder if the local authority will – will be able to, you know, do real – really accurate, dedicated assessments in the future.'*

(Former recipient)

Experiences of working with social workers that were felt to lack sensitivity during reassessments were also considered to be challenging. Some participants found remarks by social workers upsetting and worrying, which added to their anxieties around reassessments.

*'The social worker from social services ... was saying, "Well our criteria is different. We look at survival, the ILF look at quality of life." I was quite worried'*

(Former recipient)

The format and requirements of some LA reassessments were felt to be undermining. Some former recipients described reassessments which forced them to focus on all the things they could not do as affecting their confidence. Others described LA reassessments that involved having their care needs observed and verified by unfamiliar social services staff as intrusive and felt as if these were taking away their dignity.

*'They said they was going to send somebody in to monitor me, didn't they? A stranger to monitor me. Well it's your dignity, you know what I mean? They took away all my dignity and I was worrying.'*

(Former recipient)

In contrast, assessments carried out by ILF assessors in the past were not described as being undermining. Instead ILF assessors were found to be sensitive, which was attributed to their levels of experience of conducting such assessments.

## 5 New LA arrangements

This chapter initially outlines the new arrangements under local authorities (LAs) and then describes the implications of the Independent Living Fund (ILF) closure and post-closure arrangements for former recipients. The chapter draws on interview data with former recipients and proxy interviews with family carers.

### Key findings

- The new LA arrangements can broadly be grouped into three categories: an improved, matched or reduced package of care compared with the arrangements under the ILF.
- Knowing the outcome of reassessments reduced or removed anxiety about the closure, especially if the care package had stayed the same or was better. However, a level of anxiety and uncertainty remained for those awaiting an outcome of an ongoing review, appeal or complaint. Anxiety and worry about the closure also remained for those on reduced packages.
- The monetary transfer from ILF to LAs was experienced as smooth; major disruptions to receiving payments were not reported.
- Improved, matched and slightly reduced packages under the new arrangements enabled individuals to maintain the level of support and care they received prior to the closure. These participants retained a similar level of choice and control over their care and did not report major changes to their independence.
- Those with a heavily reduced package of care experienced multiple changes as a result, including: loss of paid care and support; an increased reliance on unpaid care; changes and restrictions to daily activities, including less support for engaging in leisure activities. Heavy reductions in care affected some people's physical and health. Participants on reduced arrangements reported lower trust in the social care system.
- The ILF closure brought about wider concerns about the social care system. Former recipients felt vulnerable to future reductions to funded care and support due to a perception that LA social services were under-resourced and have restricted budgets. This feeling of vulnerability was compounded by being reliant on the LA as their only funding source. Participants anticipated that they would need to 'fight' to maintain the care package they need in the future. This vulnerability was experienced regardless of the current arrangements and was felt even by those with improved and matched packages.

### 5.1 New arrangements

As outlined in the previous chapter, all former ILF recipients underwent a reassessment by their local authority adult social care services to assess their care needs and develop a care plan to establish their new arrangements. New LA arrangements can broadly be grouped into three categories: an improved, matched or reduced package of care compared with the arrangements under the ILF. New arrangements did not appear to differ for Group 1 or Group 2 ILF recipients.

#### 5.1.1 Improved package

An improved package of care related to receiving an increase in funding or care provision. An increase in funding did not necessarily equate to receiving more care, as a higher award might have been awarded to cover increased care costs. However, participants reported being 'better off' as they did not need to top-up the cost of care with their own money.

#### 5.1.2 Matched package

Matched care packages refer to former recipients receiving the same level of support and care as they had received prior to the ILF closure. The amount of funding may not have been equal to that received under ILF, but access to, and receipt of care had remained at the same level.

Others that received a matched award included; those that were initially offered a reduced package but following an appeal, complaint or request for reassessment, were awarded a matched arrangement; and those that were on a matched award at the time of interview but were awaiting a conclusion to an ongoing review. While some participants undergoing a review were hopeful of an improved or matched outcome, there were others that expected a reduction. Their expectations' of the outcome of the review appeared to influence their views and experience of the ILF closure.

#### 5.1.3 Reduced packages

A reduced care package refers to a decrease in the amount of funding awarded compared with the award received when the ILF was in existence. There were gradients of reductions ranging from small changes (e.g. a weekly care package reduced by two hours) to substantial decreases (e.g. none of the care previously funded by ILF being funded. This could equate to a weekly care package reduced by half, or entire elements of care such as night care being removed).

Alongside those that were awarded a reduced package, this group also includes individuals that were awarded matched funding for the first year following the ILF closure but were awarded a reduced package as a result of a routine 12-month care review by the LA. Additionally, this group includes individuals that had opted-out of receiving care under the LA, a decision taken in light of being awarded a reduced care package.

## **5.2 Smooth transfer – positive aspects of the transition**

Former recipients and proxy interviews with family members outlined elements of the post closure arrangements that worked well or were felt to be particularly successful, which are discussed below.

### **5.2.1 Matched funding following the announcement of the closure**

When the closure was announced in March 2014, the government committed to safeguard ILF awards for a further 15 months. The decision, therefore, did not have any immediate impact on former recipients' ILF awards. Providing they still met the eligibility conditions, they continued to receive the award until the ILF closed on 30 June 2015. Although the announcement of the closure brought about a level of anxiety for former recipients, they were appreciative that the funding did not cease immediately. The matched funding for the initial period provided a level of security and protection from the potential effects of the closure and was reported to be a positive aspect of the management of the closure.

### **5.2.2 Seamless money transfer**

An overarching finding across interviews was that the monetary transfer from ILF to LAs was smooth. There were no major reported gaps in receiving payments. However, it should be noted there were former recipients undergoing a review process at the time of the interview and in some of these cases funding had been halted or temporally stopped. Looking across former recipient interview data it appears that these issues can be attributed to isolated errors on the part of their local adult social services. Participants had anticipated that there may be funding gaps during the transition and disruptions to accessing services and care provision but these concerns were not realised. The seamless monetary transfer between the ILF to LAs in July 2015 was considered to be a successful transition.

### **5.2.3 One social care support system for all**

The ILF was closed to new applicants after December 2010. In acknowledgement of this, there was a view that the ILF closure was fair to the wider population of disabled people with complex needs, especially those excluded from applying since 2010. Although former recipients were generally not in favour of the fund's closure, one positive aspect noted by family members taking part in proxy interviews was that access to social care funding were now the same for all people with social care needs.

### **5.2.4 Continuity of care**

Former recipients were pleased to maintain continuity of care during the transition and under the new arrangements, enabled by retaining the same care staff or commissioned services. Interviews revealed that some care staff had worked with former recipients over a number of years and had formed important relationships – both personally and professionally. Retaining care staff and commissioned services reduced disruption to daily activities. Those with reduced care packages that were able to retain some or all of the same staff, enabled some familiarity and some continuity of care, although less flexibility and control over the range of activities that could be performed (see Section 5.3.3).

## 5.3 Changes as a result of the closure

This section discusses the changes and consequences of the ILF closure and new arrangements, as reported by former recipients (and family carers that participated in the study on behalf of former recipients).

### 5.3.1 Working with LA social services and social workers

Although former recipients (in the most part) had dealings with their LA social care department when the ILF was in existence, the closure of the ILF meant a greater reliance on the LA to meet their support needs. Participants reported that LAs had different ways of working compared with the ILF. The changes and challenges encountered by former recipients of working with LAs are described below.

#### Contacting LAs and social workers

As mentioned in Chapter 4, former recipients recounted frustrations of working with social services and social workers. These centred on communication, continuity of care and staff knowledge and experience of working with disabled people with complex or rare conditions. Social workers were described as difficult to contact; former recipients were issued with centralised telephone numbers for their LA adult social care department and were generally not given a direct contact number for social workers. Phone calls and left messages would sometimes not be returned, resulting in the need to chase social services for the required information.

*'I kept phoning them up and I phoned one number that was on this form and I couldn't get through so I phoned another department and they said, "Oh no, we don't use that number anymore." Well, why is it on the form? And it costs money. You're on the telephone for hours and it's just a nightmare to, so you just hope nothing ever goes wrong.'*

(Former recipient)

By contrast, ILF were said to be easy to contact via a dedicated local telephone number, often reaching the same person who knew of the former recipient, or who could access their information easily.

#### Trust in social workers

A general complaint among participants was not having a dedicated social worker, which provided a further challenge to working with social services. Working with different social workers could result in having to re-explain health conditions, care packages and care needs. Furthermore, social workers were, by and large, perceived to lack understanding of complex disabilities and rare conditions. This affected former recipient's trust in their ability to conduct thorough needs assessments and ensure appropriate care packages would be put in place.

An important difference in people's reactions to changes in provision was dependent on whether former recipients and family members were involved in discussion about potential modifications to care packages, or whether they felt changes were imposed on them without consultation. This had implications on former recipients' willingness to trial changes, or feel negatively about them.

People also reported positive experiences with some social workers, as part of the reassessment and more generally. However, this did not negate the view held about social workers' large workloads and the perceived pressure by LAs to minimise spending.

Under the ILF, former recipients had worked with the same local ILF assessor over a number of years. ILF assessors were considered to be knowledgeable and experienced in working with disabled people. Relationships with the ILF were described as collaborative and supportive and participants felt confident that they would advocate on their behalf to ensure their care needs were met.

### LA accounting procedures

The accounting procedures for the ILF and LA were different. LAs accounting procedures for personal budgets were described as more restrictive. Participants reported that this difference reduced their control and flexibility in how allocated funds could be used. In contrast, participants reported that ILF could be used more flexibly; e.g. ILF could be used for household cleaning, gardening, bonuses for carers, taxi fares for carers to get home safely at night, or to pay for a family member to go on holiday with them. Such spending is not permitted under LA spending guidelines.

Furthermore, accounting and auditing procedures were experienced to be stricter and more bureaucratic under LAs which contributed to the feeling that LAs did not trust care recipients to use allocated funds appropriately. Former recipients reported feeling more trusted under ILF accounting procedures.

*'... with social services you feel they're always breathing down your neck. "Where have you spent this penny? Where have you spent that penny? How much interest does the bank give you? Where have you spent it?" ILF went, assessed you every two years ... "Have you got enough hours?" "Yes." "Can I just see your books?" So all she wanted to see was bank statements and a rota. I keep a diary of who works what and she looked at that and said, "It's all fine," and just left me alone.'*

(Former recipient)

The change in how the ILF and LAs account for spending of allocated funds was a point of frustration, but also a point of adjustment for people that were new to direct payments. For example, new users of direct payments reported being unclear about what they could and could not use this funding for, and felt worried that they may be penalised for unintentionally mispending funds. Participants mentioned trying to seek clarity on how to use and maintain accounts for direct payments from a social worker or by contacting LA adult social care services, but had not received guidance at the time of the interview.

### Caps on hourly rates for care staff

Former recipients within some LAs reported their LA had an upper limit on their contribution to the hourly pay rate for carers; such restrictions had not been experienced under the ILF. As a result, carers that were previously funded by ILF could be on a higher rate of payment than the LA upper limit. This was not a universal issue, but was reported by former recipients in particular LAs. Pay caps could present a difficulty for participants: firstly, it meant potentially having to reduce hourly pay for carers under the new arrangements, although the caring tasks remained the same. Secondly, participants were of the view that 'good care costs' and explained that the hourly rate may need to be higher at particular times and days of the week; for example, care at weekends, evenings and bank holidays. Caps or upper

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limits on how much a carer could be paid were felt to be obstructive in being able to work with 'good' carers or continuing to work with existing carers, who, under ILF, were paid at a higher rate. Participants working with self-employed carers reported that competitive hourly rates helped to attract and retain good quality care staff, and those obtaining care via an agency also perceived there to be a correlation between hourly pay for carers and quality of care. In some cases, former recipients or their family 'topped up' carer pay using their own funds to bypass LA upper limits. However, this option was not considered to be a viable long-term solution, nor was it an available option to those without the necessary financial resources.

### **Direct payments**

Direct payments are a form of personal budget whereby the LA assess and award individuals a budget for them to spend on services to meet their eligible care needs. They were a key feature of post-closure arrangements. Those previously in receipt of personal budgets prior to the closure welcomed their continued use. Direct payments were viewed positively among existing users as they were a familiar form of funding. New users, however, required time to adjust to this new approach. Nonetheless, existing and new users alike agreed that a key benefit of personal budgets was that they provided a flexible and person-centred method of receiving and paying for care services. For example, they allowed people to retain the choice and flexibility to work with self-employed carers. New users discussed the benefit of receiving direct payments in advance, rather than in arrears, as was the case with ILF. A further benefit of direct payments, among digitally confident individuals, was the ease of managing financial information online, especially if they had previously provided ILF accounting information by paper. Conversely, there were users that were digitally excluded and did not have the access to, or know how to bank online.

### **12-month care plans**

Under the new arrangements and as part of the Care Act (2014), LAs have a statutory obligation to reassess support and care plans of their adult social care customers on an annual basis. Under ILF, some recipients recalled few or no LA assessments and could have ILF assessments once every two years. Participants that were concerned about the financial pressures on LA adult social care departments reported feeling worried that annual reviews provided LAs the opportunity to reduce their care packages every 12 months. This view spanned across participants groups, including those with improved, matched and reduced packages. For these participants, having a care plan in place for a year at a time reduced their sense of security about retaining their support services. As a result, these participants described feeling less able to plan their care over the longer-term. This left some participants feeling that they would be 'living one year to the next' under the new LA arrangements. It should be noted that this difference is partly due to the ILF closure, as they were now reliant on only one source of support (LAs). However, this change is also due to the introduction of the Care Act and the statutory obligation for annual care reviews; a change which is independent of the ILF closure.



### 5.3.2 An improved or matched package

Being awarded an improved package of care under the new LA arrangements was reported to be an unexpected outcome, but one that former recipients were satisfied with. Similarly, those with a matched arrangement (with the exception of those undergoing a review that they expected would result in a worse outcome) were also satisfied with their new arrangements.

*‘If you’d asked me six months ago, I would have said bring back ILF but now, talking from me personally, it’s a good thing.’*

(Former recipient)

Participants had feared they may encounter cutbacks to their care package that would impinge on their independence, choice or control over their care. Such concerns were not realised among those with improved or matched packages. Former recipients that had initially been offered a reduced package, but had undergone (or were undergoing) an appeal or complaint procedure had experienced concern and worry during this period of uncertainty. In some cases a matched award was achieved, in others the appeal remained ongoing at the time of the interview.

Not only did stable or better care packages enable people to have their care needs met, it also allowed people to continue participation in leisure activities that they had accessed when in receipt of ILF. Former recipients and family carers (in proxy interviews) noted that a benefit of the ILF was that it funded and encouraged disabled people to engage in a range of activities of their choice. The announcement of the closure and fear of funding cuts caused worry that leisure activities may be restricted under the new LA arrangements.

*‘... he was part of the majority of the world, he was not part of the disabled community, and the ILF had given him that sort of independence and he wanted to continue that.’*

(Proxy interview with family carer)

These findings indicate that one of the main issues during the closure was fear of the unknown. Knowing the outcome of reassessments reduced or removed anxiety about the closure, especially if the care package had stayed the same or was better.

However, as discussed above (see Section 5.3.1), there remained a level of worry, even among those with better than expected outcomes, about the security of maintaining care packages (at the level of need) in the long term. These concerns were expressed in the context of the ILF closure, an awareness of wider austerity measures and increasing demands on LA social care services. Former recipients, regardless of their new arrangements, wondered whether they may encounter challenges or reductions to their care package at their next LA care review.

### NHS Continuing Healthcare

During the reassessment process, LAs checked former recipients’ eligibility for being awarded National Health Service (NHS) Continuing Healthcare (CHC). Care packages that were fully, or partly, funded by NHS CHC were generally linked to having an improved package of care. Participants that were under review for, or had been awarded NHS CHC, reported feeling a greater sense of security in the long-term about their care as they were not reliant on the LA as their primary funding source. Former recipients reported further benefits of NHS CHC, such as receiving new equipment and having access to other health and social care professionals (e.g. an occupational therapist).

### 5.3.3 A reduced care package

Among participants that had a reduced care package, there were gradients of reductions ranging from small changes to substantial decreases. Participants that had received a small reduction to the overall package were generally satisfied with the outcome under the new arrangements as they were able to retain a similar standard of living pre- and post-ILF. However, those with larger and more substantial reductions reported how the changes had affected them (presented below).

#### Loss of paid care and unmet care needs

A reduced care package resulted in former recipients losing established and long-term care workers, either because the new arrangements left them with too few hours and pay, or because the element of care they provided had been removed entirely (e.g. night care or one-to-one care no longer being funded). Loss of established carers affected former recipients in a range of ways, including having to recruit, train and adjust to new carers, or having unmet care needs.

There was a financial implication for those that now self-funded their care fully or partially. As mentioned above (see Section 5.3.1), there were instances where former recipients or their family paid more towards the cost of care than they had under the ILF. This was not considered financially viable in the long-term, nor was it an option for everyone that had a reduced care package.

Greater reliance on unpaid care was a reported consequence of heavily reduced care packages. Unpaid care was provided in the most part by family members. Family and friends had tended to provide some unpaid care under the ILF, but the number of hours of unpaid care had increased under the new arrangements. Participants also cited examples of formal carers (i.e. paid carers) providing unpaid care, as their funded hours had been cut but they remained in need of care. Former recipients felt uneasy about a greater reliance on unpaid care and wanted the option to fund care that they needed, or offer respite to unpaid family and friends. They also believed it was not sustainable in the long-term.

*'You want [carers] you can trust, rely on, and have confidence in. That's not there now. And having to have [family members] to come and help out a bit more doesn't make me feel good at all. I feel I'm putting on them, and my condition shouldn't put on other people. That's what all of this was set up to help, and ... it's just not doing it. I'm very upset and annoyed ... I honestly feel that I've gone backwards.'*

(Former recipient)

In some cases LAs had sought to provide alternative provision in place of carers. For example, a carer previously paid for by ILF provision had been replaced with a remote on-call care system for falls or emergencies, and in another instance a commode was provided in the place of carer support. However, former recipients did not always feel these alternative provisions met their needs. This resulted in reduced trust in the LA's ability to provide them with the care they felt they needed.

One reported benefit of the LA reassessments was that some of the LA social workers discussed support options for unpaid family carers, such as having a carers' assessment or advice on carers' benefits.

Participants drew comparisons with the higher package of care that they had under the ILF. They described the previous higher award as having a positive effect on them and their family relationships as it enabled them to have more paid care and to take part in activities independently from their parents or partners. This lessened the extent to which former recipients felt dependent on others.

### Health implications

The sample included some former recipients that reported they had experienced adverse physical and mental ill health in anticipation of the closure and once the new reduced arrangements were in place. A heavily reduced package was reported to have a range of health implications including loneliness, particularly for those living alone; weight loss; and frailty due to worry, or due to the physical demands of having to perform everyday activities without the support of a carer. This was reported to be detrimental to their mental health and wellbeing.

### Changes to daily activities

A reduced care package had direct implications for the types and range of activities that former recipients could engage in. Participants reported that such post closure arrangements had compromised the level of choice and control they had over their daily activities. Former recipients had to prioritise their needs, typically prioritising personal care and attending medical or official appointments over social activities and participating in activities outside their home. For example, the loss of one-to-one care previously funded with ILF support had resulted in former recipients having to stop volunteer and paid employment. They also reported spending more time alone, particularly those that lived by themselves; worrying about safety, particularly at night time; and having unmet care needs.

Having a bigger package of care under the ILF had been positive for the former recipient's independence. They felt it had supported them to have their care needs met, which included participation in social activities and spending time out of their home. Former recipients with significant reductions to their care package described that under the new, reduced care package, they felt like their life was an 'existence'.

*'I won't be able to make myself any food without help, so basically they'll just help me to get up in the morning ... what am I meant to do in the daytime? I don't want to be a prisoner in my own house. I've got a mobility car outside but I can't drive it without a driver ...'*

(Former recipient)

### Changes to housing

As noted in the methodology section of this report (see Section 2.2.4), the study sample included one participant that had moved into residential care following the closure of the fund. The individual moved from independent living in the community to a residential setting. This move was attributed to the ILF closure combined with changes to local services (e.g. closure of local respite service). Under the new arrangements the individual had received matched funding, but due to a change in their condition, required increased funding which was not met by the LA. The proxy family interviewee was concerned that the independence of the former recipient may be compromised as a result of the move to residential care. It is difficult to say whether this individual's living circumstances might have been different if the ILF had not closed. Furthermore, this research is unable to draw wider conclusions based on a sample of one.

### Trust in the social care system

Those that had received a reduction in care, particularly those that had experienced a substantial reduction, conveyed less trust in the LA social care system. They felt "lied to" as the ILF and LA communications they had received had suggested to them that the funds would be transferred from central government to LAs. They therefore did not understand why their care and support had been reduced. As a result, there remained a level of anger about the closure of the Fund.

There was also a lack of trust in the LA being able to meet their needs in the future if their health condition deteriorated. Former recipients described how the reduction in care packages and the closure of the ILF made them feel like disabled people were a 'burden' on society.

*'We're a burden to society now, all they want is people who are fit enough to work ... I don't like the way I am ... but I have to accept the way I am'*

(Former recipient)

### 5.3.4 Wider concerns about the new arrangements

Participants, regardless of whether they had an improved, matched or reduced care package, presented a number of possible implications of the new arrangements. These concerns were speculative in nature and although at the time of interview had not been realised, they were nevertheless important to former recipients. These wider concerns are presented below.

#### Meeting care needs in the future

Former recipients felt more vulnerable since the ILF closure and were concerned about the potential for future reductions to their care and support packages. This was discussed by participants regardless of their current arrangements, mentioned even by those with improved and matched packages. Reliant on a single funding source coupled with a perception that LA social services had restricted budgets formed the basis of these concerns. Furthermore, recipients felt that the closure of the fund signified a shift in emphasis in funding decisions from 'meeting needs' to 'meeting budgets'. Participants therefore anticipated that they would need to "fight" to maintain the care package they need in the future. This view was reinforced by first-hand experiences of having to fight to obtain LA funded services.

*'... social services, they have some lovely people working for them but they're just out of control, they're underfunded, under resourced and out of control'*

(Proxy interview with family carer)

During reassessments in some LAs, former recipients and proxy family carers had encountered social workers suggesting that the former recipient could move into residential care as a cheaper alternative to living in the community. This had caused distress for former recipients and family members. Although they were living independently at the time under the new arrangements, they remained worried that social services may pursue this at future reviews. In the eventuality that residential care might be needed, there was also concern that LA social services would base the decision on cost, rather than suitability for that particular individual.

*‘[Under ILF I] Never had to worry about whether [the former recipient] could stay at home. But now, it’s a case of you can’t afford to pay the carers, one social worker said, you’ll have to sell the house and move into a nursing home. Well, [the former recipient] is only young, she doesn’t want to be in a nursing home’*

(Proxy interview with family carer)

### Meeting urgent care needs

LA social services were perceived to be slow decision makers and reactionary in approach. Former recipients worried about future urgent care needs and that the LA would not be able to meet an unexpected need or rapid request, for example if the former recipient’s health condition changed, or a family carer unexpectedly became unwell. There was a sense that the ILF was better set up for such situations. In some cases, participants had experienced ILF support in emergency situations. By comparison, LAs were reported to be difficult to make contact with for general enquiries and slow at returning calls and finalising care plans. These experiences with the LA had influenced people’s poor perception of their ability to deal with urgent care requests. It also fed into wider concerns about local respite services’ closures in some geographic areas. When the ILF was in existence, participants stated that they would have made contact with the ILF in the first instance, rather than their LA. It may therefore be possible that concerns about urgent care needs under the LA may not be realised.

### Displacement of care and support needs

Reductions to care packages were considered to be short-sighted. Those that had encountered a reduction or anticipated a reduction in the future speculated that reduced home care may result in more hospital admissions or contact with general practice (GP) doctors due to falls and ill health, therefore displacing the cost of care upon other healthcare services.

*‘the government, what they don’t think when they do these cuts, is that if you don’t look after a person, you can have falls, you feel more ill, you end up calling ambulances ... but if you’re cared for, and you’ve got people that does these hours for you, they begin to know exactly what your needs are, and things work so well, and I think in the end you do save money.’*

(Former recipient)

### Loss of ILF advocacy support and wider functions

The ILF was more than a monetary fund for some former recipients. Former recipients described the wider functions of the ILF and the broader sense of loss they felt due to its closure. Firstly, the ILF was seen as a trusted advocate for the needs of disabled people with complex conditions. Former recipients cited examples of the ILF communicating with LAs on their behalf to ensure they received the support and care they needed. Furthermore, they were viewed to be particularly supportive of individuals that were non-verbal or lacked cognitive or mental capacity. Secondly, the ILF were used as an information and signposting service; some participants would contact the ILF in the first instance to find out about local and national services for providers of equipment, for example. Thirdly, the ILF had local user committees which some participants had been members of. The closure of the fund resulted in a closure of these committees too. The committees were made up of ILF recipients and participants described feeling empowered by them.

## 6 Conclusions

Former recipient views and experiences of the Independent Living Fund (ILF) closure ultimately hinged on the new arrangements under the local authority (LA). Those that were awarded improved, matched, or a small reduction in their care and support package had maintained the level of support and care they received prior to the closure, as well as a similar level of choice and control over their care. They also reported limited or no changes to their independence.

It was the period of the uncertainty about whether the ILF would close that generated fear and anxiety among former recipients, which continued until an outcome about the new LA arrangements was received. Anxieties centred on what the new LA arrangements would be and whether all their care needs would be met. Former recipients felt fearful that care and support previously funded under the ILF might be cut entirely, which would have significant implications for daily activities and ability to live fulfilling and independent lives.

While ILF communications about the closure were reported to be clear and frequent, satisfaction with LA communications varied. Former recipients experienced different transitional journeys, dependent on the approach taken by their LA. Some participants reported positive and relatively smooth transition journeys, with supportive social workers and quick notification of their new arrangements quickly. Others reported a lack of clarity about planned LA assessment procedures and poor experiences with LA social workers. Undergoing an appeals or complaints process exacerbated the stress and worry former recipients felt. LAs reported that appointing a dedicated delivery team that included staff with prior knowledge of the ILF aided their understanding of the potential sensitivities involved and seemed to facilitate a smooth transition.

Those with a heavily reduced award experienced multiple changes as a result. They argued that these reductions were unfair and denied them the opportunities to participate fully in society. For example, due to the loss of paid care and support, they had an increased reliance on unpaid care provided by friends and family. They encountered changes and restrictions to daily activities, including less support for engaging in leisure activities, work and volunteering. LAs noted that face-to-face meetings with former recipients and their next of kin to sensitively discuss alternative provisions, changes and reductions to care helped to negotiate these difficult decisions.

The ILF closure brought about wider concerns about the social care system, regardless of the new arrangements, and was felt even by those with improved and matched packages. Former recipients felt vulnerable to future reductions to funded care and support. These worries were linked to being solely reliant on one funding source and the perception that LA social services are under-resourced and have restricted budgets. Participants therefore anticipated that they would need to 'fight' to maintain the care package they needed for the future.

The findings suggest that poor experiences of the transition in particular LAs could have potentially been improved by better communications with former recipients about how and when the arrangements would be decided. Future anxiety related to annual reassessments might likewise be mitigated by similar improvements. Furthermore, the perceived quality of the workforce undertaking assessments affected participants' experiences. Having high quality staff that were experienced and showed sensitivity about an individual's circumstances facilitated a positive transition journey. LA staff suggested that a concrete measure of success would be gained at the next scheduled care reviews, to assess whether care awarded met needs and check whether there had been any unintended consequences (e.g. increased burden on family carers).

# Appendix A

## Topic guides

### P12041

## Independent Living Fund post-closure evaluation

### Topic guide for former recipients

**Key objectives of the research:**

- To monitor the impact of ILF closure across a range of former ILF recipients.
- To consider unintended consequences which have resulted from ILF closure.
- To consider the care outcomes ILF recipients have achieved following closure.

**To provide evidence against the following:**

- Identify the support outcomes achieved by former ILF recipients during receipt of ILF, and post-closure.
- Understand the perceived impact on the level of support available now that the ILF has been withdrawn.
- Understand and compare how support previously available with ILF funding compares with support available now.
- Document care outcomes post-ILF (including former recipients' experiences on delivery and standard of care and the extent to which former recipients are living independently).

*The following guide does not contain pre-set questions but rather lists the key themes and sub-themes to be explored with each participant. It does not include follow-up questions like 'why', 'when', 'how', etc. as it is assumed that participants' contributions will be fully explored throughout in order to understand how and why views, behaviours and experiences have arisen. The order in which issues are addressed and the amount of time spent on different themes will vary between interviews and according to individual experiences.*

### **Introduction (5 minutes)**

*[INTERVIEWER INSTRUCTIONS IN ITALICS]*

#### ***Explain who we are***

- Introduce yourself, NatCen and the study.
- Check they have read the study information leaflet.

NatCen is an independent social research organisation and has been commissioned by the Department for Work and Pensions (DWP) to find out how the closure of the Independent Living Fund (ILF) has impacted the care and support outcomes of its former recipients.



### ***Explain voluntary nature of participation***

- Taking part is completely voluntary, and will not affect any benefits you receive in any way.
- You can stop the interview at any time.
- If you don't want to answer a question, that's fine too.

### ***Explain interview format***

- Mostly 'open' questions – we are very much interested by what **you** think.
- When we're asking you questions, there are no right or wrong answers –it is not a test; we're just interested in your perspective.
- If there are any questions you feel **unable** to answer, that's fine.
- **The focus of the interview is the closure of the ILF** and how the support you receive now compares to the support accessed under the ILF. You may have undergone other benefit changes over the years, but as far as possible we'd like you to think about the ILF and its closure.
- Timing of interview (60 minutes).
- If you need a break at any point, just let me know.

### ***Recording of Interview***

- Digital recording of interviews – ***check participant is happy with this***. Just to save taking notes and make sure we have an accurate record of what you've told us.
- What you say in the interview is confidential. We will not tell anyone what you have said. Disclosure of harm: The only situation where we might have to share what you have said with someone else is if we believe either you or someone else might be at risk of serious harm.
- Report, use of quotations, anonymization – we won't use your name in any report.
- If there is anything you don't want included or quoted that's fine – you can just let us know.

### ***Consent***

- ***Check that the participant has read the information sheet.***
- ***Check if participant has any questions.***
- ***Check if happy to proceed.***
- ***Make sure to record verbal consent to take part, on the digital recorder.***

### **DIGITAL RECORDER ON**

- Record your introduction.
- Confirm that we've explained to them:
  - What the interview is for.
  - That taking part is voluntary.
  - That we would like to record it.
  - That we won't use your name in reports.
- Ask them to confirm they're happy to proceed.

## Independent Living Fund – Post-closure Review

### 1. Key background info (5-10 minutes)

**AIM:** BRIEFLY, find out about living arrangements, employment status and health condition; now and at the time of ILF closure (after 30th June 2015).

To start off with I would like to hear a bit about you:

- **Living arrangements:**

- Who they live with – alone/with others + who:  
~ *any dependants/children.*
- Type of housing – e.g. home ownership/tenant/sheltered accommodation.
- Length of time in current accommodation.
- Check for any changes to living arrangements since the time of ILF closure.

- **Employment:**

- Ask whether they are in or out of work.
- **If employed:** nature of job, how long employed for, full-time or part-time, self-employed or not, one or multiple jobs.
- **If unemployed:** for how long, previous employment.
- Check for any changes to employment status since the time of ILF closure.

- **Health condition(s):**

- What health condition/s do they have.
- How long they have had each condition.
- Briefly explore in what ways these affect them day-to-day.
- Check for any changes in health condition since the time of ILF closure.

### 2. Support available when in receipt of ILF (15 minutes)

**AIM:** Map the range and level of support accessed whilst in receipt of ILF, including experiences of delivery and standard of care and the extent to which they felt they could live independently.

**\*\*Interviewer:** keep checking in with participant about whether supports described were available to them as a result of ILF, local authority or something else.

Thinking of the support that was available to you while you were receiving ILF (before July 2015):

- Map what kinds of things did they used their ILF for:
  - *Explore types of support services accessed.*
  - *Equipment and aids.*
  - *Anything else ...*

- Delivery of support and standard of support/care:
  - **Where – in/outside of home.**
  - **How often was this support available.**
  - **What times of the day was support available.**
  - **Who provided this.**
  - **Level of choice, control and flexibility of care available.**
- Satisfaction with the care received:
  - **Reasons for satisfaction/dissatisfaction.**
- Living independently: ILF was set up to help people live independently.
  - Did the ILF help them to live as independently as they wanted to/in what ways did it help:
    - ~ **Support/care.**
    - ~ **Mobility.**
    - ~ **Social activities.**
  - What does living independently mean to them.
  - Were there any forms of support unavailable to them under ILF/any unmet support or care needs.

### 3. Transition and support available now (post ILF closure) (15 minutes)

**AIM:** Understand and compare how support previously available with ILF funding compares with support available now.

Thinking of the support that is currently available to you now that the ILF has closed (since July 2015):

- **Communication of closure:**
  - how changes to their care package were communicated to them by local authorities.
- **ILF/DLA/PIP:** very briefly ...
  - When they stopped receiving ILF.
  - Whether they are currently receiving DLA or PIP.
- **Map changes** in support and care since closure of ILF:
  - Changes in types of support they access/receive.
  - Changes in delivery of support and standard of support/care:
    - ~ **Where – in/outside of home.**
    - ~ **How often support is available.**
    - ~ **Times of the day support is available.**
    - ~ **Who provides this.**
  - **Changes in the level of choice, control and flexibility of care available.**

## Independent Living Fund – Post-closure Review

- **Explore reasons for any changes in support:**
  - **Related to ILF closure or something else.**
- Satisfaction with the care they receive now:
  - **Reasons for satisfaction/dissatisfaction.**
- Explore whether there are any ...
  - forms of support unavailable to them under new arrangements.
  - unmet support/care needs.

### 4. Perceived impact of ILF closure (15 minutes)

**AIM:** Explore participant reflections on how the closure of the ILF has affected them.

- Explore what the closure of the fund has meant for them:
  - **Were they affected by closure.**
  - **How were they affected by it .**
  - **What have been the main changes for them.**
  - **Have there been any positive changes.**
- Explore impact of ILF closure on levels of independence:
  - Has their level of independence changed:
    - ~ **How + why.**
  - What could help them to be as independent as they would like to be, now.
- What has been most helpful to them in managing the closure of ILF.

#### **Ending the interview (2 minutes)**

- Thank them for their time.
- Next steps (i.e. interview will feed into report which will be shared with minister and reported to parliament).
- Check that they are happy for us to use the interview and if there is anything in the interview they prefer was not quoted.

## P12041

### Independent Living Fund post-closure evaluation

#### Topic guide for Local Authority stakeholders

**Key objectives of the research:**

- To monitor the impact of ILF closure across a range of former ILF recipients.
- To consider unintended consequences which have resulted from ILF closure.
- To consider the care outcomes ILF recipients have achieved following closure.

**To provide evidence against the following:**

- Identify the support outcomes achieved by former ILF recipients during receipt of ILF, and post-closure.
- Understand the perceived impact on the level of support available now that the ILF has been withdrawn.
- Understand and compare how support previously available with ILF funding compares with support available now.
- Document care outcomes post-ILF (including former recipients' experiences on delivery and standard of care and the extent to which former recipients are living independently).

*The following guide does not contain pre-set questions but rather lists the key themes and sub-themes to be explored with each participant. It does not include follow-up questions like 'why', 'when', 'how', etc. as it is assumed that participants' contributions will be fully explored throughout in order to understand how and why views, behaviours and experiences have arisen. The order in which issues are addressed and the amount of time spent on different themes will vary between interviews and according to individual experiences.*

#### **Introduction (5 minutes)**

*[Interviewer instructions in italics]*

#### ***Introduce yourself, NatCen and the study***

NatCen Social Research is an independent social research organisation and we have been commissioned by the Department for Work and Pensions (DWP) to explore views and experiences of the closure of the Independent Living Fund

In addition to former recipients' views, we also want to understand the experiences of local authority staff involved in working with the ILF around the time of closure. We would like to find out more about the arrangements put in place by different local authorities to handle the closure of the fund. To do so, we are conducting interviews with staff in a number of local authorities in England.

The interview will last between 30 and 45 minutes.

## **Independent Living Fund – Post-closure Review**

### ***Explain voluntary nature of participation:***

- Taking part is completely voluntary.
- You can stop the interview at any time.
- If you don't want to answer a question, that's fine too.

### ***Explain interview format:***

- Mostly open questions.
- We're interested in **your** perspective.
- Explain that you are not an expert in ILF or any other disability benefit; so you may need to ask them to fully explain what they mean by particular terms or acronyms.
- If there are any questions you feel unable to answer, that's fine.

Timing of interview (approximately 30-45 minutes).

### ***Recording of Interview***

- Digital recording of interviews – check for agreement. Just to save taking notes and make sure we have an accurate record of what you've told us.
- Caveats to anonymity – we will take measures to protect your anonymity, e.g. we won't use your name or name the LA/CC in the final report, or in any quotations. However, if you hold a very specific role or your LA/CC or your LA/CC is very different to others, you or the LA/CC may be identifiable.
- If there is anything you don't want included or quoted that's fine – you can just let us know.

### ***Consent***

- Check that the participant has read the information sheet (sent via email).
- Make sure to record verbal consent on the digital recorder.
- Check if respondent has any questions.
- Check if happy to proceed.

### **DIGITAL RECORDER ON**

- Record the introduction.
- Confirm that we've explained to them:
  - What the interview is for.
  - That taking part is voluntary.
  - That we would like to record it, and
  - That we won't use any names in reports.
- Ask them to confirm they're happy to proceed.

## 5. Intro and key background info (5 minutes)

**AIM:** Find out about current role within Local Authority/County Council and about involvement with the ILF prior to closure

To start off with I would like to hear a bit about your current role:

- Current role and length of time in role.
- Key responsibilities:
  - particularly in relation to the eligibility and use of disability benefits.
- What was their involvement with the ILF.

## 6. Local authority/county council management of the ILF closure (15 minutes)

*Aim: explore how the closure of the fund was managed.*

When the ILF closed last summer, LAs adopted a range of different approaches to support former ILF recipients.

- **How was the closure managed locally.**

### Communication plan of local arrangements to ILF recipients

- When did you communicate the closure and new arrangements.
- How was this done.
- Number, frequency.
- Method: leaflets, mailshots, targeted emails.
- What was communicated.
- Accessibility of communication for all recipients.
- Reflections on communication.
- What worked well.

### Transition management

- When did the transition period take place.
- What did the transition look like for former ILF recipients – journey:
  - *any differences between the transition in Group 1 and Group 2 claimants.*
- Explore any temporary measures introduced to cover the transition period:
  - What were these.
  - How long were these in place.
- If **reassessments** involved:
  - What does this look like/what is involved.
  - Involvement of LA/CC.

## Independent Living Fund – Post-closure Review

- What does the process look like for former users.
- Appeals/reclaims.
- What non-financial help LA have given to former recipients:
  - *e.g. supported housing, support for carers.*
- Anything that worked particularly well:
  - for LA/CC.
  - for former recipients.
  - were there any challenges/what were these/how were these addressed.

### Current situation

- How are former ILF funds being allocated:
  - Funding allocations.
  - Eligibility criteria.

### Feedback

- Has there been any feedback about the closure/transition.
- What was the feedback:
  - from staff.
  - former recipients.

## 7. Overall reflections of the ILF closure (5-10 minutes)

**Aim:** *to explore the general views and experiences of the ILF closure, paying attention to positive as well as negative experiences.*

- Overall what would you say has been your experience of the closure of the ILF:
  - What went well.
- Has the transition been as you expected.
- Biggest impact of closure for ...
  - LA/CC.
  - Former ILF recipients.
- Is there anything else.

### **Ending the interview**

- ***Thank participant for his/her time.***
- ***Next steps (i.e. interview will feed into report which will be shared with minister and reported to parliament).***
- ***Check that they are happy for us to use the interview and if there is anything in the interview they prefer was not quoted.***