

One year on:

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Evaluating the  
impact of the  
closure of the  
Independent  
Living Fund

Inclusion London

According to Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, as quoted in article 1.19 of the Care Act 2014 Statutory Guidance, States such as the UK who are signed up to the Convention should:

“recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

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## CASE STUDY

Steven has Cerebral Palsy spastic quadraplegia. He had been in receipt of 24 hour a day care for a number of years. Following the assessment it was reduced by 14 hours and a quarter a day to ten hours and three quarter hours. Following an appeal, he was re-assessed and it was accepted that he had 24/7 care needs. However, the package provided was so small that it would not allow carers to receive minimum wage. It would have left a severely disabled person in an extremely vulnerable position as he would be left at home without any support at all.

## CASE STUDY

“I had my reassessment last week. It was very poorly executed and arranged. I had received an email the week before from a care manager claiming to have tried to contact me by phone several times and needing urgently to perform the review. I spoke to her on the phone the following day and once again she stressed the urgency of the matter. I pointed out to her that the reality was that the ILF transfer was not a sudden thing and that they have had the last three years to plan it yet they wait until less than a month before end date to contact me! in order to satisfy her urgent need i had to arrange leave from work in order to do it.

On the day of the review she arrived with a second person without asking which i felt was extremely rude. When i challenged her on this she just casually informed me it was all last minute. During the course of the visit i pointed out that the whole closure of the ILF was causing immense stress that was compounded by the lack of any clear message from LA - i didn't really feel that either of them took my comments seriously.

At two points during the interview the idea of using a conven and inco pads as an alternative toileting solution was raised. This i felt was completely inappropriate given the fact i have no medical need for either and no continence issues at all. It wasn't directly said but it felt like it was being put forward as the solution to cutting of hours, even over night stays.

There was never any effort to reassure me or to offer me advocacy of any sort. I have no idea what the outcome of the reassessment will be and now just have to wait.”

– Former ILF recipient

# 1. Foreword by Dr Jenny Morris OBE

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For the first time in the history of modern social policy, we are in danger of going backwards in terms of the support available to disabled people. From the early 1970s, disabled individuals and their organisations campaigned for, and won, important changes to policy and legislation which – for many – meant for the first time they could aspire to the same ‘ordinary lives’ as non disabled people.

One of those achievements was the Independent Living Fund, set up in the 1980s as a direct result of opposition to changes in the benefit system. Using eligibility criteria which applied wherever someone lived, the ILF topped up the funding available from local authorities, in recognition that those with the highest levels of support needs require assistance which local authorities did not provide. Moreover, resources were provided in a way which enabled people to have choice and control over the support they needed.

The ILF made a major difference to people whose needs had previously meant their only options were residential care or a very limited life for them and their families.

The Fund closed in 2010 to new applicants and no-one monitored what has happened since then to people who would previously have qualified for support. In the meantime, local authority adult social care budgets have been cut back, undermining their ability to deliver the Care Act’s promise of well-being, choice and control to those whose ILF funding transferred last year to local councils.

In such circumstances the existence and work of organisations like Inclusion London – who have researched and written this report – is vital. Using Freedom of Information requests to London boroughs about how they have used the money transferred from the ILF, a picture emerges of a post code lottery. Where a person lives can mean the difference between, on the one hand, the ability to carry on working, volunteering, caring, socialising and, in contrast, leading such a restricted life that your human rights are at risk.

This report provides valuable evidence in our continuing struggles for the right to levels of support necessary to protect and promote disabled people’s human and civil rights. We need strong advocacy organisations such as Inclusion London. It is particularly worrying that the majority of the London borough disabled people’s organisations contacted for the report wished to remain anonymous – an illustration of their fear about speaking out about their local Council on whom they are often dependent for funding.

Internationally, nationally and locally disabled people’s human and civil rights have been protected and promoted by our organisations. In these days, when those same rights are under sustained attack, all of us are in even greater need of the organisations that, like Inclusion London with this report, are drawing everyone’s attention to the consequences of a failure to invest in disabled people’s lives and opportunities.

## LOCAL AUTHORITY CASE STUDY: HAMMERSMITH AND FULHAM

"As a council, Hammersmith & Fulham is serious about protecting and enhancing the wellbeing of its residents. Through our decision to step in and protect the Independent Living Fund after its closure by central government, we have secured on-going support for disabled people in the borough.

"We were able to do this by making a wide range of savings and cutting wasteful expenditure, including cutting the number of senior managers, cutting the costs of office space we use, scrapping council magazines and reducing the PR budget.

"Through the decisions we've taken, we've been able to support our residents, including enabling disabled people to keep the life-changing funding they deserve."

### CASE STUDY

"In September 2010, I started my university degree. I was really looking forward to starting my course and experiencing the student life, but as a disabled student I needed additional help. I lived in halls of residence for three years but not without its challenges. In order to live in halls I needed my personal assistant (PA) to live with me full time. However, the cost of my PA's room at university was very expensive. I heard about the ILF a year prior to going to university so I thought that I could use it to help pay for the room. I was shocked to find out that the fund had been stopped that year. As a result of that, it became very difficult to pay for the carer's room. A charity kindly helped to pay for half the cost of the room, and it was very stressful trying to find payment for the other half. Eventually I had to use my student loan to pay for the other half, when it should have been used for other expenses.

The absence of the ILF also meant not having enough money to pay for the amount of care that I needed at university. My PA had to live with full time, but my local authority did not give me enough care hours. If I had the ILF it could have helped to pay towards my care. Due to the local authority's refusal to pay for the carer's room and refusing to give me extra hours, my mum had to help with my care at the weekends to give my PA a break. This was frustrating for my mum and I because she had to drive down to the university every weekend, when she also the main carer for my Grandmother who has dementia. This made me very angry because I felt that I was not having the full university experience since I had to rely on the help of my mum a lot. Having the ILF could have made life a lot easier and stress free for my family and I. This in effect contributed to extra financial worries during my time at university. I believe that by removing the ILF it is preventing disabled people from living fully independent lives. We have the right to have the same quality of life as our non-disabled peers; we just need extra help to do this, which is what the ILF can give us. The ILF can help pay for essentials such as care, which is extremely important for disabled people, because having the right care helps on our path towards independence."

– Disabled young person who missed out on the ILF

## 2. Executive Summary

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- 2.1 The Independent Living Fund (ILF) was shut permanently on 30 June 2015. One week before wheelchair users tried to storm the House of Commons chamber during Prime Minister's Question time in a last ditch attempt to prevent closure. Disabled people receiving support through the ILF who are all too familiar with the day to day realities of the mainstream care and support system, were concerned that closing the ILF would mean a removal of essential support.
- 2.2 In order to mitigate the negative impact of the closure of the ILF, the government transferred to English Local Authorities (L.As) the exact spend on ILF payments to recipients in their area for the period 01 July 2015 – 31 March 2016. In May 2016 the government confirmed another four years of funding through a "Former ILF Recipient grant" . Neither of these grants was ring-fenced however, leaving the decision on how to spend it up to individual LAs.
- 2.3 With so much uncertainty over the future for former recipients of the ILF it has been important to monitor and record the impact of the closure. Furthermore, the transition experiences of ILF recipients cast an unparalleled light on how the new flagship Care Act 2014 is being implemented.
- 2.4 There are huge differences in the way different Councils responded to transfer from the ILF, which makes it difficult at this stage to generalise about the impact of closure. However, discernible trends have emerged as former ILF recipients continue to share information, experiences and peer support. It is also possible to draw comparisons between challenges taken by former ILF recipients against LA decisions following reassessment.
- 2.5 This report seeks to evidence the impact of the closure with a focus on the situation in London. It brings together statistical analysis from Freedom Of Information (FOI) requests sent to all 33 London boroughs with findings from a survey sent out to London Deaf and Disabled People's Organisations (DDPOs) as well as qualitative evidence provided by former ILF recipients concerning their experiences of transfer to Local Authority (LA) support.
- 2.6 Freedom Of Information requests were sent to all 33 London boroughs in June 2016 asking for information about the situation in their Local Authority area following closure of the Independent Living Fund (ILF). All but one London borough (Hackney) responded. Enfield responded with information provided in response to a similar previous request.
- 2.7 The overwhelming conclusion to be drawn from the FOI responses is the extent to which a dramatic post code lottery operates across London for former ILF recipients. While a number of Councils have made a decision to maintain pre-ILF closure levels of support, others have made substantial cuts suggestive of a

systematic approach of ‘levelling down’ packages. These are cuts made despite the four years of funding provided by the government through a “Former ILF Recipient grant”. Another clear finding from analysis of the FOIs is the amount of time that has been wasted through ineligible referrals for Continuing Healthcare (CHC) funding by certain boroughs. This reflects a lack of consistent practice across LAs as other boroughs have in place eligibility screening systems before referral.

- 2.8 Additionally, the FOIs provide little or no evidence of enforced moves into residential care as a result of the closure of the ILF. To date no London borough has to our knowledge attempted to impose a capping policy as exists elsewhere in the country.
- 2.9 Surveys were sent out to London Deaf and Disabled People’s Organisations in Inclusion London’s contact database. 14 organisations (11 borough specific and three pan-London) returned completed surveys and one other submitted detailed information in freeform text.
- 2.10 The majority (8 out of 12) wished to remain anonymous which indicates a fear of repercussions from speaking out negatively about their local Councils.
- 2.11 A relatively high number of DDPOs were unaware of their Council’s position on ring-fencing the Former ILF Recipient grant. Such uncertainty causes anxiety and distress to former ILF recipients awaiting decisions upon which their futures depend.
- 2.12 The existence of a postcode lottery is demonstrated by the divergent experiences between different boroughs, with some DDPOs scoring their LAs as managing transition positively with no impact on former ILF recipients and others reporting negative management and negative impact.
- 2.13 While most DDPOs reported a negative impact of closure on former ILF recipients, none pointed to a corresponding positive impact on other social care users which could have occurred from an evening out of resources between those who previously had support through the ILF and those that did not.
- 2.14 DDPOs have also experienced a negative impact as a direct result of the closure of the ILF, as former ILF users have needed more support placing an additional burden on resources.
- 2.15 Comparison of evidence gathered through comparison of the Freedom Of Information (FOI) responses, Deaf and Disabled People’s Organisations (DDPO) survey, and examples of lived experience submitted by former ILF recipients has led to a number of themes emerging:
- Post-code lottery for former ILF recipients across Local Authorities.
  - The detrimental impacts of the ILF closure on former ILF recipients, ranging from distress and anxiety to removal of essential daily support.



- The lack of consistent practice across different Local Authorities regarding referrals for CHC funding.
- Limitations of the mainstream care and support system and failings in the implementation of the Care Act.
- The value of the model of support provided by the Independent Living Fund.
- The importance of Deaf and Disabled People’s Organisations for making Deaf and Disabled people aware of and supported to exercise their rights.

2.16 Despite assurances to the contrary in the run up to June 2015, the closure of the ILF has directly resulted in the removal of support from Disabled people with high support needs. Where support packages have so far remained the same this is due to specific funding for the support of former ILF recipients from central government (funding that was only secured through active campaigning by Disabled people, our organisations and our allies). In conclusion, the closure of the Independent Living Fund represents a clear step backwards in independent living support for Disabled people.

2.17 The ability and competence of local authorities to implement the Care Act 2014 is highly questionable. Experiences of former ILF recipients going through reassessment reveal assessment processes that fail to put the Disabled person at the centre and funding decisions that remove choice and control and undermine well-being – the primary duty and principle of the Care Act . The experiences of former ILF recipients mirror those of adult social care users who missed out on or would not have been eligible for the ILF and are consequently struggling with inadequate levels of support that severely curtail choice, control and independence.

2.18 The Care Act 2014 says many good things but lacks enforcement mechanisms so that it is up to individual Disabled people – those who face the biggest barriers in society – to hold LAs to account. Even where individuals have the rare confidence and support to challenge LA decisions and initiate legal action the changes to legal aid restrict the number of people for whom this is an option.

2.19 There is an urgent need for a radical rethink of how Disabled people are supported to live independently. Disabled people who use independent living support must be at the forefront of developing ideas and with adequate resources for meaningful engagement.

2.20 This also needs to happen quickly, before the memories of what effective independent living support looks like and how much Disabled people can contribute when our support needs are met fade into the distance.

## CASE STUDY

Joan previously received a personal budget of 45 hours per week (including 13 hours ILF). During the Winter months she would return home to Sri Lanka with her husband and one of her PA's (the PAs take it in turns to go) so that she could access care that is not available to her here. This care includes physiotherapy 2-3 times per week in her home, and alternative therapies for her back. These breaks were also medically approved as the warmer climate reduces her symptoms and delays the progress of her illness.

As she stays with family, her husband is able to take a break from his caring role. This is the only break he gets all year. These breaks were fully funded by Joan, so the only cost to the Council was the hours that her PA continued to work. Following her review this year, Joan's hours have been reduced to 26; a 42% percent cut to her budget, and the Council have said she is no longer allowed to take her PA away with her. This means her husband will not be able to have a full rest, and she is at risk of losing her PAs as they will not be paid whilst she is away.

The Council have instead provisionally offered a sit-in service throughout the year which will actually cost them more money, and would not meet Joan's and her husband's needs. Over the years Joan has saved the Council a lot of money as she has never needed to use her contingency fund, as the plan in place was robust enough.

## CASE STUDY

Miss C is severely disabled, looked after by her 86 year old mother. ILF originally provided 34 hours of support with the local authority providing another two, 5 days at a day centre and 66 days respite.

When ILF ceased, Wiltshire local authority cut what was 36 hours to 24.5 hours, Mrs C complained and wrote to her MP and after a review the hours were increased to 28.5 with the 0.5 hours to be saved for contingencies such as ill health. 28 hours, although an improvement is still far short of the ILF package and still difficult to manage.

## CASE STUDY

Wayne is 44 years old. He suffered from tumours in his brain which had left him with significant physical impairments. He had been receiving 72.5 hours to meet his needs including ILF funding. Following his re-assessment his package was cut to 38 hours per week. The reason given for the decision was that the Independent Living Fund had finished. This would have left the person in a position where his hours would be taken up with his personal care and subsistence needs. As a person who has many interests and is very involved in the community it would have left him isolated at home and unable to maintain his quality of living.

### 3. Introduction

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- 3.1 The Independent Living Fund (ILF) was shut permanently on 30 June 2015. One week before wheelchair users tried to storm the House of Commons chamber during Prime Minister's Question time in a last ditch attempt to prevent closure<sup>1</sup>. Earlier that month Minister for Disabled People, Justin Tomlinson, had written in the Guardian that it was inaccurate to claim "support made available to some disabled people under the independent living fund is to be removed" and that transfer of that support to Local Authorities (LAs) would mean "it will be administered in a way better able to take account of variations in local circumstances and services". Tomlinson stated that to suggest otherwise was "scaremongering"<sup>2</sup>.
- 3.2 Disabled people receiving support through the ILF and all too familiar with the day to day realities of the mainstream care and support system<sup>3</sup> were not reassured. Assertions that support would not be removed as a consequence of transfer contradicted the judgments in a succession of legal challenges<sup>4</sup> against the Department for Work and Pensions' decision to close the Fund, which pointed to "the inevitable and considerable adverse effect... particularly on those who, as a consequence, will lose the ability to live independently."<sup>5</sup> Indeed the DWP defence throughout the legal proceedings rested on the Minister having paid "very close attention to the potential negative impact on existing users... of the ILF."<sup>6</sup>
- 3.3 In order to mitigate the negative impact, the government transferred to LAs in England<sup>7</sup> the exact spend on ILF payments to recipients in their area for the period 01 July 2015 – 31 March 2016<sup>8</sup>. In May 2016 the government confirmed

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1. <http://www.bbc.co.uk/news/uk-politics-33252828>

2. <https://www.theguardian.com/society/2015/jun/11/impact-of-changes-to-disability-benefits>

3. In February 2016 the Local Government Association warned that there will be a shortfall of more than £2.9bn in care services by 2020.

4. Claimants lost the first case taken against the DWP's decision to close the ILF in April 2013 but won on appeal in November 2013. In March 2014 the Minister for Disabled People retook the decision to shut the fund and a second legal challenge was launched. The High Court ruled the decision lawful in December 2014 with no scope for appeal.

5. A copy of the judgment by Justice Andrews DBE can be found at: <http://lexisweb.co.uk/cases/2014/december/r-on-the-application-of-aspinall-and-others-formerly-including-bracking-v-secretary-of-state-for-wor>

6. As above

7. The devolved administrations in Northern Ireland, Scotland and Wales made their own arrangements with the ILF transition funding they received from central government. All committed to maintain pre ILF levels of support for former ILF recipients and Scotland set up its own Scottish Independent Living Fund with the intention to open to new applicants.

8. See Appendix A for the breakdown of ILF transition grants paid to English Local Authorities

another four years of funding through a “Former ILF Recipient grant”<sup>9</sup> <sup>10</sup>. Neither of these grants was ring-fenced however, leaving the decision on how to spend it up to individual LAs<sup>11</sup>.

- 3.4 With so much uncertainty over the future for former recipients of the ILF it has been important to monitor and record the impact of the closure. The campaign to save the ILF<sup>12</sup> was never just about those Disabled people who received support through the fund (who numbered around 16,500 at the time of closure). The fact that without the ILF, Disabled people with high support needs were unlikely to be able to continue to live independently with choice and control over their lives was a reflection of the state of adult social care and the failings of the personalisation agenda. Transfer from the ILF, which provided effective support with overwhelmingly high user satisfaction ratings while operating with significantly lower overheads than LAs<sup>13</sup>, over to the mainstream care and support system has proved an early test of the Care Act 2014. This came into force in April 2015, just three months before the ILF shut. The transition experiences of ILF recipients cast an unparalleled light on how the Care Act is being implemented.
- 3.5 This report seeks to evidence the impact of the closure with a focus on the situation in London. Further research is needed in order to gauge how representative the picture in London is compared to the rest of England. The campaign to save the ILF was particularly active in London and strong local campaigns resulted in a number of boroughs committing to ring-fence the ILF grant money from central government to maintain pre-closure levels of support for former ILF recipients<sup>14</sup>. However, as the findings in this report evidence there is dramatic contrast between the way transition has been handled from borough to borough and this picture of a postcode lottery fits with anecdotal evidence from Deaf and Disabled People’s Organisations around the country<sup>15</sup>.
- 3.6 It is hoped that the findings in this report can in some small way lead to improvements in the independent living support provided to Disabled people so that once again, regardless of impairment, Disabled people can aspire to the same life chances as other people and a quality of life that goes beyond ‘clean and feed’.

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9. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/523090/160414\\_Annex\\_A\\_-\\_Former\\_ILF\\_Recipient\\_Consultation\\_response.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/523090/160414_Annex_A_-_Former_ILF_Recipient_Consultation_response.pdf)

10. See Appendix B for the breakdown of Former ILF Recipient grant funding by Local Authority area

11. Freedom Of Information requests submitted by Disability Rights UK in January 2015 to all English Local Authorities found that most Councils were not planning to ring-fence: <http://www.disabilityrightsuk.org/news/2015/april/most-councils-will-not-ring-fence-ilf-resources>

12. <https://www.facebook.com/ILFpostcard/>

13. The final Independent Living Fund annual report and accounts (2014-15) reported a user outcome satisfaction of 98% and overheads of just 2%: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/435825/ilf-annual-report-2014-2015.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/435825/ilf-annual-report-2014-2015.pdf)

14. For example Hammersmith/Fulham and Islington.

15. Bristol Disability Equality Forum report that no reassessments have taken place yet and no cuts made whereas members of Equal Lives in Norfolk have had significant cuts following transfer.

## CASE STUDY

I have been receiving assistance from people for 30 years now, and in that time I have learnt some lessons

This is a summary of the main points concerning my journey changing from ILF to Direct Payments:

- I had to chase for a Social Worker to come out and start the process
- The Social Worker concerned did not really understand what she was doing
- Lack of communication and the guidelines kept changing
- The way the financial contribution is worked out is different
- With ILF if your ILF package was £100 and my contribution was £20 I got £80
- Now it is I have to put £20 into the pot to make the package £100
- Having to go through the whole process, and the checks to make sure I was eligible
- We have a scheme called Enablement who come in and work with the person for six weeks to see if there are ways the person can be more independent. I have a progressive condition, and did not listen to the "time slots". The "Just Checking" system was put in to make sure again I needed the help
- Having to describe a typical day, I have no typical day and how long does it take to do x., y and z It is life
- Had an assessment for CHC money and in the report it stated that I:
  - Have good sitting balance
  - Only use a wheelchair for outside use
  - Can weight bare (In fact I am a full time power chair user and have not been able to weight bare for 40 years.)
- Assistance is assistance whether, personal, domestic or social
- Yes I had a drop in hours from 60 to 46 and less money to work with
- The hourly rate that is allocated in my area is £10.96, which I a joke when to get good workers you have to pay a good wage
- Sending in a new agency who "won" my contract without me meeting them first, the agreement was my package was 7 to 8, yet they thought it was ok to send somebody at 8.15
- There was an overpayment made in my award and the direct payment finance team thought it was OK to deduct it at source without telling me so instead of getting £100 I got £20. Alongside the fact the advice notices are not user friendly
- The whole process took a year, mega stress

## 4. How this report was put together

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- 4.1 This report brings together statistical analysis from Freedom Of Information (FOI) requests sent to all 33 London boroughs with findings from a survey sent out to London Deaf and Disabled People's Organisations (DDPOs) as well as qualitative evidence provided by former ILF recipients concerning their experiences of transfer to Local Authority (LA) support.
- 4.2 The FOI requests<sup>16</sup> asked questions relating to the removal of support following reassessment, referrals for Continuing Healthcare (CHC) funding, complaints received about the transfer process and numbers of Disabled people moved into residential care as a direct consequence of the closure of the ILF.
- 4.3 The survey was sent out to London DDPOs on Inclusion London's contact database. Inclusion London defines a DDPO as an organisation where at least 75% of the Board and 50% of the staff team identify as Deaf or Disabled people<sup>17</sup>. Survey questions<sup>18</sup> focused on the impacts of closure of the ILF as observed by DDPOs in the course of their day to day work, also the impact of closure on the organisation itself.
- 4.4 This report also contains examples from the lived experience of former ILF recipients. These shared experiences have come from individuals in touch with Inclusion London either through the #SaveILF campaign or through having contacted us to find out about their rights under the Care Act. In the majority of cases individuals have asked to remain anonymous and without inclusion of any information by which their LA could be identified for fear of reprisals. It should be noted that the examples of lived experience have been contributed by former ILF recipients based across England and are not restricted to London. This is because the independent living campaign is national and the examples used are valuable reflections of themes common across LAs in or outside of London. Where examples have been used from former ILF recipients in the devolved nations this is stated.
- 4.5 The report ends with a series of recommendations drawn from consideration of the collated evidence.

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16. For a copy of the FOI request sent to each borough see Appendix C.

17. <https://www.inclusionlondon.org.uk/about-us/what-is-a-ddpo/what-is-a-ddpo/>

18. For a copy of the survey sent to London DDPOs see Appendix E.

## CASE STUDY

“Before I was referred for funding from the Independent Living Fund I lived without having my most basic needs met, spending hours unable to have a drink or go to the toilet, without dignity and without any quality of life, existing between TV and hospital.

I can't bear to think of a return to life without these opportunities.

Unfortunately in my job I see many people who are suffering the dreary lifestyle that I had once had as they have missed the chance to apply for ILF funding. One client says that she feels she is treated "worse than a dog - at least dogs get taken for a walk every day" - as she spends all but a couple of hours a week in bed. She doesn't have a package flexible enough to have someone around to help her back to bed when her muscles no longer allow her to maintain her position in her wheelchair. The hour that she can spend in her chair, while the care worker is doing housework, she drives from room to room like a caged animal "just to make sure the other rooms are still there"!

I have no doubt that ILF funding would have made her life much, much better.”

– Former ILF recipient

## CASE STUDY

“Apparently all I need is to be clean & fed. My County Council will only pay for 'hands on personal care' which can all be condensed into a couple of hours a day. I don't have the right to expect any quality of life or a clean home. I will be kept all clean & shiny but if my home is a cesspit that doesn't matter.

[The social worker] told me all LAs (Local Authorities) knew the closure of the ILF was a cut - no more, no less. And the main reason why it was closed in her opinion? Because now each individual's LA has to be the one to break the news that their lives are too expensive. Her words were: "...they transferred responsibility for Social Care funding to the LAs so that they (central Government) would not have to tell anyone what was going to happen. It's a cut, pure and simple.

When I went along to a DWP consultation when the ILF closure was announced they told us that it made sense to have one funding stream only and it most definitely wasn't a cut. A barefaced lie, in other words.”

– Former ILF recipient

## 5. Background

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### 5.1 ORIGINS OF THE FUND

- 5.1.1 The Independent Living Fund (ILF) was set up in 1988 for “people who are severely disabled” and on low incomes enabling them to pay for “domestic care” to live in the community when the alternative was residential care. This was a response to opposition to the government’s abolition of the Domestic Needs Allowance as a way of reducing the benefit bill.
- 5.1.2 The ILF was set up as a government-funded non-departmental public body operating as an independent and discretionary trust fund managed by a board of trustees.
- 5.1.3 The government thought that only about 250 people would qualify but by 1992, over 22,000 people were receiving an ILF grant and the original £5million budget had reached £97 million<sup>19</sup>. Although a commitment was made to maintain payments for those already in receipt of the ILF since 1988 this original fund was closed to new applicants in 1993 and replaced with a new ILF with restricted eligibility including the condition that social services provide a weekly financial contribution.
- 5.1.4 The ILF was the first “cash for care” scheme established in the UK and was ground-breaking in giving funds directly to Disabled people to purchase their own support.
- 5.1.5 In 1993 Jenny Morris published research, comparing the experiences of people who were dependent on traditional services with those who received grants from the Independent Living Fund or cash payments from their local authority<sup>20</sup>. She says: “The contrast was striking in terms of people’s access to privacy and a family life, and to the opportunities they had for participating in society: ILF grants gave people control over the support they needed and meant their human and civil rights were protected and promoted”<sup>21</sup>.
- 5.1.6 Developments in social care support provision gradually extended opportunities for Disabled people to exercise choice and control over the support they used. The 1996 Community Care (Direct Payments) Act made it legal for Local Authorities to give Disabled people “cash for care”. The introduction of Individual Budgets through the personalisation agenda took the principle further, seeking to embed choice and control at the heart of mainstream social care provision<sup>22</sup>.

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19. <https://jennymorrisnet.blogspot.co.uk/2012/01/defending-independent-living-fund.html>

20. Morris, J. 1993. *Independent Lives? Community Care and Disabled People*, Macmillan.

21. <https://jennymorrisnet.blogspot.co.uk/2012/01/defending-independent-living-fund.html>

22. The 2005 Government report ‘Improving the Life Chances of Disabled People’ set out an ambitious programme for achieving disability equality in four key areas including improving independent living



5.1.7 In 2006 Melanie Henwood and Bob Hudson completed a review of the ILF, on behalf of the Department for Work and Pensions (DWP), to consider how it fitted with Individual Budgets<sup>23</sup>. At that time the fund supported more than 18,000 people, at an annual cost of £264m. The reviewers concluded it was “anomalous to retain a separate non-departmental public body with responsibility for a large amount of social care expenditure operating in parallel to the mainstream world of independent living”<sup>24</sup>. Testimony collected from ILF recipients and their families in the course of the review showed how highly they valued the ILF and its life-changing impact. The report nevertheless pointed to the greater freedoms that the concept of ‘self-directed support’ being piloted through individual budget schemes had the potential to offer.

## 5.2 DECISION TO CLOSE

5.2.1 In March 2010, with demand out-stripping available budget, the ILF announced that from 01 May 2010 it would begin to limit new applications to people working at least 16 hours a week and also increased the threshold sum that local authorities were required to meet in order to access ILF funding from £320 to £340 per week<sup>25</sup>. The announcement sparked an influx of applications hoping to get in before the changes in eligibility and by June 2010 the ILF had run out of money and closed temporarily to new applications for the financial year 2010-11.

5.2.2 In December 2010 the then Minister for Disabled People Maria Miller announced the permanent closure of the ILF to new applicants. The Government claimed that as an independent discretionary trust for social care, the ILF model was ‘financially unsustainable’ and a consultation on the future of the fund was promised in 2011<sup>26</sup>.

5.2.3 That consultation did not materialise until 2012 following pressure from campaigners. Disabled people and allies opposed to the closure were concerned that shutting the ILF was no more than a cost cutting measure and not the ‘reform’ the Government was presenting it as<sup>27</sup>. They argued that the Henwood and Hudson review, which the Government was using to justify its decision,

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support through the introduction of individual budgets: <http://dera.ioe.ac.uk/7261/>

23. M Henwood, B Hudson, Review of the Independent Living Funds, Department for Work and Pensions, 2007.

24. <http://www.communitycare.co.uk/2007/03/13/independent-living-fund-is-past-its-prime-write-bob-hudson-and-melanie-henwood/>

25. <https://www.gov.uk/government/publications/ilf-priority-applications-and-threshold-sum-equality-impact-assessment>

26. For the text of the ministerial statement see: <http://base-uk.org/policy/news/independent-living-fund-permanently-closed-new-applicants>

27. Papers later declassified for the first legal challenge confirmed that the Government deliberately adopted the “narrative of reform” while only intending a single year of transition funding to help Local Authorities take on their new responsibilities. See: <https://disabilitynow.org.uk/2013/04/30/the-end-of-the-right-to-independent-living/>

was outdated with the developments in mainstream care and support that the report promised never having materialised, and that implementation of the recommendation to close the ILF would be dangerous within the current political-economic climate<sup>28</sup>.

- 5.2.4 On the 18th December 2012, following consultation, the Government announced that the ILF would close on 31st March, 2015 with funding transferred to local authorities in England and the devolved administrations in Scotland and Wales<sup>29</sup>.

### 5.3 LEGAL CHALLENGES

- 5.3.1 In response, ILF recipients launched a legal challenge on the grounds that the DWP had failed to consult properly and assess the full impact on Disabled people's ability to live independently. In April 2013 the High Court upheld the decision to close<sup>30</sup> but an appeal subsequently over-turned this judgment in November 2013.
- 5.3.2 The judges in the Court of Appeal found that the DWP had failed to fulfil its duty, under section 149 the Equality Act 2010, to have "due regard" to the need to promote equality of opportunity between Disabled and non-Disabled people in its decision to close the fund and that briefings given to then disability minister Esther McVey by officials did not adequately make clear "the potentially very grave impact" the closure could have. Lord Justice McCombe said responses to the consultation indicated that "independent living might well be put seriously in period for a large number of people"<sup>31</sup>.
- 5.3.3 Following the undertaking of a new equality impact assessment, the next Minister for Disabled People, Mike Penning, announced in Parliament on 6th March 2014 that the ILF would now close on 30th June 2015 and that funding transferred to local authorities in respect of their new responsibilities would not be ring-fenced. A fresh legal challenge was launched but was dismissed in the High Court in December 2014 with Justice Andrews finding that information presented to the Minister had identified in "sufficiently unambiguous terms" the impact of the ILF's closure<sup>32</sup>.
- 5.3.4 Due to the three month timeframe for initiating Judicial Review proceedings, a legal challenge against closure to new applicants in December 2010 had not

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28. <http://dpac.uk.net/2013/11/why-the-henwood-and-hudson-report-failed-in-justifying-the-closure-of-the-independent-living-fund/>

29. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/184151/closure-of-independent-living-fund-eia.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/184151/closure-of-independent-living-fund-eia.pdf)

30. Bracking & Ors, R (on the application of) v Secretary of State for Work and Pensions & Anor [2013] : <http://www.bailii.org/ew/cases/EWHC/Admin/2013/897.html>

31. Stuart Bracking & Ors v Secretary of State for Work and Pensions [2013]: <http://www.bailii.org/ew/cases/EWCA/Civ/2013/1345.html>

32. Aspinall, Pepper & Ors, R (on the application of) v Secretary of State for Work and Pensions & Anor [2014]: <http://www.bailii.org/ew/cases/EWHC/Admin/2014/4134.html>

happened. A complaint to the United Nations under breaches of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was instead taken by two people (details below) who would have been eligible for the ILF but missed out<sup>33</sup>. A formal response to the individual complaint has never been received, but it can be surmised that the complaint contributed to the investigation of the UK for breaches of the UNCRPD carried out by the UN in October 2015<sup>34</sup>.

Nicky Baker, age 30, is a qualified auditor working within a disabled people's organisation as well as studying part-time for a degree. Although eligible for support from the ILF, the Fund was closed the day after she telephoned for an application form. The social care package she received from her Local Authority did not provide the support she needed to live an independent life, for example to go on dates with her boyfriend without having her parents there or to take part in sufficient training for the high level of powerchair football she reached.

Dr Melanie Wilson Jones received a substantial amount of support including from the ILF after sustaining a brain injury. She made such progress that her needs decreased and thus her support was reduced. However following a road traffic accident in 2011 she sustained a further brain injury requiring someone to be with her constantly. Unable to get support from the ILF, she was reliant on her husband who works full-time and her 16-year-old daughter to make up the extra hours of support she needed for evenings and weekends.

## 5.4 TRANSFER

- 5.4.1 In order to mitigate negative impacts of closure on ILF recipients, the ILF put into place ahead of transfer a comprehensive support programme including face to face visits, assessments and information and guidance throughout the process<sup>35</sup>. The ILF also produced a report aimed at local authorities presenting the learning developed by the ILF during the 27 years it was operational<sup>36</sup>.
- 5.4.2 Meanwhile local authorities in England were awaiting confirmation of how much they would receive from central government through the ILF Transitional grant for the period 01 July 2015 - 31 March 2016. It would seem at some point there was a suggestion that the amount transferred to each LA would be the total spend

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33. <http://dpac.uk.net/2015/03/uk-disabled-people-appeal-to-the-un-over-independent-living-fund-closure/>

34. <https://www.theguardian.com/society/2015/oct/20/un-inquiry-uk-disability-rights-violations-cprd-welfare-cuts>

35. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/439711/ilf-your-transfer-guide-england.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/439711/ilf-your-transfer-guide-england.pdf)

36. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/432380/twenty-seven-independent-living-fund-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/432380/twenty-seven-independent-living-fund-report.pdf)

on ILF recipients in their area at the time the fund closed minus 3% to account for “natural attrition”<sup>37</sup>. However, in an interview on BBC Look North ahead of the 2015 General Election, then Chancellor George Osborne told ILF recipient Helen Johnson that the ILF would be transferred “pound for pound” to local authorities<sup>38</sup>.

- 5.4.3 On 7 July 2015, one week after the ILF shut, the Department for Communities and Local Government wrote to English LAs confirming the amounts they would each individually receive through the ILF Transition grant. These amounts accounted for the full spend on payments to ILF recipients in their areas<sup>39</sup>.
- 5.4.4 In the run up to closure, Disabled people put pressure on individual Councils to ring-fence the Transition grant funding to support for former ILF recipients, with some local campaigns making use of the 2014 local elections to secure pledges<sup>40</sup>. A series of FOIs revealed that the majority of Councils were not planning to ring-fence the transition funding to the support of former ILF recipients. The majority were planning to ring-fence to the Adult Social Care budget but some were not planning a ring-fence at all<sup>41</sup>. FOIs carried out by Inclusion London highlighted the wide variation in approaches to transfer that LAs were planning with some stating they had already completed reassessments of all former ILF recipients in their area under the Care Act 2014 before the fund closed and others setting a target date of March 2016<sup>42</sup> for the same.
- 5.4.5 The dramatically different ways in which different Councils responded to transfer from the ILF makes it difficult at this stage to generalise about the impact of closure. However, discernible trends have emerged as former ILF recipients continue to share information, experiences and peer support through the communication structures originally set up for the #SaveILF campaign.
- 5.4.6 At a recent meeting in Birmingham<sup>43</sup> common experiences came to light including difficulties caused by care managers failing to understand the employment obligations of Direct Payment users, for example trying to cut hourly pay rates for Personal Assistants without notice periods and being unaware of legislation relating to the National Minimum Wage and overnight support.
- 5.4.7 It is also possible to draw comparisons between challenges taken by former

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37. Waltham Forest continues to maintain that a reduced amount was transferred in spite of documentary evidence to the contrary: <http://www.mirror.co.uk/news/uk-news/anguish-mum-son-betrayed-tories-7222660>

38. [www.youtube.com/watch?v=ucBoLsx6bMo](http://www.youtube.com/watch?v=ucBoLsx6bMo)

39. For the grant breakdown see Appendix A

40. The incoming Labour administration in Hammersmith and Fulham, for example, also committed to the abolition of homecare charging.

41. <http://www.disabilityrightsuk.org/news/2015/april/most-councils-will-not-ring-fence-ilf-resources>

42. <https://www.inclusionlondon.org.uk/campaigns-and-policy/comment-and-media/freedom-of-information-requests-show-chaos-ahead-of-ilf-closure/>

43. Independent Living campaign national meeting held 29.07.2016 at St Martin’s in the Bullring, Birmingham

ILF recipients against LA decisions following reassessment, throwing a light upon the delivery of social care support administered by local authorities and implementation of the Care Act.

Mitchell Woolf of Scott Moncrieff has provided legal support in a number of cases relating to former ILF recipients where reassessment has breached the Care Act 2014. Mitchell summarises the common themes he has seen arising:

- Lack of engagement with the Disabled person
- Lack of transparency
- Failure to put things in writing
- Assessors often do not consider or read the ILF assessments
- Failure to provide explanation for cuts
- Not taking views and wishes of the Disabled person as central to the assessment

5.4.8 This report seeks to take a systematic approach to evidencing the situation one year on from closure of the ILF and the impact on Disabled people who previously received support from the fund.

#### CASE STUDY

“[The] County Council ILF money is not ringfenced. They originally reassessed my son and cut his budget by £700 a week although his situation has not changed. I fought this and eventually got that money back. Then they got together with Health and the Health Authority cut his budget from £1,600 a month to £54 saying he did not need complex manual handling. Luke is quadriplegic and blind and has had complex manual handling funding for 18 years. His physical condition has worsened. We are fighting that, but they have stopped paying the money, which means he will not be able to pay his carers.”

– Family member of a former ILF recipient

## CASE STUDY

Robert (not his real name) has muscular dystrophy. He has complex needs and requires support to be available 24 hours. He has had support from the ILF since about 1990 when he was first assessed as needing overnight support. Under the ILF he got a combined support package costing £515.52/week from ILF and £509.63/week from [his LA]. That is for 70 hours per week plus sleepover support 7 nights a week. That level was agreed between Social Services and ILF in 2003 – 12 years ago.

Now they are offering him a total of £450/week (i.e. less than half, and less than even the amount the council are providing at present). This is based on 6 hours of support each day (instead of 10) and nothing at night. They seem to be suggesting he should be grateful because they have topped it up slightly from the even lower amount produced by their automatic calculator. There is no explanation about why they have nearly halved his daytime support or what has changed to justify withdrawal of night time support when he has been recognised for decades as needing this. MD is a degenerative condition and Robert's needs have increased not decreased. For example his breathing has deteriorated so much that he was becoming ill from build-up of carbon dioxide at night and now has to be on a ventilator all night.

There are various unpredictable risks and needs that the night-time support is needed for, including problems with the ventilator and he sometimes needs assistance with changing position, to avoid pressure sores and other problems. But the most common night-time need is for support with accessing the toilet. The Council want him to use pads instead so that he will be forced to be incontinent when he is not in fact. Outrageously, the email below claims that they are offering ways to 'increase your independence at home'.

Robert works 4 days a week, ironically for [his local] which is making the cut. He is a library admin staff member – has worked there for 7 and a half years.

The cut to both the daytime hours and night-time support will be absolutely devastating for him. The idea of being forced to be incontinent is a horrific attack on his dignity and well-being, and that alone has all sorts of implications in terms of health (eg it increases the risk of urinary tract infections), relationships and ability to work.

## 6. London Borough Freedom Of Information Responses

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6.1 Freedom Of Information requests were sent to all 33 London boroughs in June 2016 asking for information about the situation in their Local Authority area following closure of the Independent Living Fund (ILF). All 33 boroughs responded. Enfield responded with information provided in response to a similar previous request.

6.2 It should be noted that the accuracy of the information supplied in response to the FOIs has not been verified. In two cases the local Deaf and Disabled People's Organisation has reported to us a discrepancy between some of the answers and their experiences supporting former ILF recipients; in another the DDPO received a different answer to the same questions when posed through a Council scrutiny committee. In this latter case the reduction in the number of packages reported as being cut could be the result of successful challenges having taken place between the Committee and the FOI.

### 6.3 QUESTION 1

**How many former Independent Living Fund (ILF) recipients reside in your London Borough?**

6.3.1 The variation in numbers of former ILF recipients resident in each borough confirms that Local Authority practice with regards to ILF referrals differed from borough to borough before closure to new applicants in December 2010. For example Southwark with a population of 288,300 only has 15 former ILF recipients (1 former ILF recipient for every 19,220 residents) while Barnet with a population of 356,000 has 89 (1 former ILF recipient for every 4000 residents).

### 6.4 QUESTION 2

**How many former ILF recipients who have had community care assessments have had reductions in levels of their care package funding and/or support compared to the total they received from both the ILF and the Local Authority combined before closure?**

**Of these how many have had reductions:**

- **Of under 10%?**
- **Of between 10 and 20%?**
- **Of between 21 and 40%?**
- **Of between 41 and 50%?**
- **Of over 50%?**

- 6.4.1 The FOI responses show that 185 former ILF recipients across the capital have experienced a reduction to their support package following the closure of the ILF. The spread of individuals experiencing cuts is not spread evenly across the boroughs: the total percentage of recipients experiencing a reduction in each borough ranges from none where Councils have chosen to ring-fence the Former ILF Recipient grant to between half and two thirds experiencing a cut in other areas.
- 6.4.2 Ten boroughs (City of London, Enfield, Hammersmith/Fulham, Islington, Kingston-upon-Thames, Southwark, Sutton, Tower Hamlets, Wandsworth and Westminster) reported no cuts to any packages in contrast to four boroughs that reported reductions to over 50% of packages (Havering, Hounslow, Newham and Waltham Forest). Nine reported reductions to less than 10% of support packages (Barking/Dagenham, Camden, Croydon, Ealing, Hackney, Haringey, Harrow, Lambeth, and Redbridge), five reported reductions to 10–20% of packages (Brent, Bromley, Greenwich, Hillingdon, and Richmond), two reported reductions to 21-40% of packages (Barnet and Lewisham) and one reported reductions of between 41 and 50% of packages (Merton). One borough (Bexley) said they have yet to re-assess but of those four reassessments that had been carried out at the time of responding, three remained the same and one was cut by over 50% due to misuse of funds. Another borough (Kensington/Chelsea) said they do not hold the information we were requesting.
- 6.4.3 Eight boroughs reported cuts to individual packages of 50% or more (Barnet, Greenwich, Hackney, Hillingdon, Hounslow, Lambeth, Newham and Waltham Forest). Of these one borough, Waltham Forest, accounts for 38% (16 out of 42) out of the total across London.
- 6.4.4 Four boroughs reported increases in support packages resulting from reassessments following closure of the ILF (Croydon, Newham, Sutton and Waltham Forest). Newham reports that 40% (17 out of 43) support packages have had an increase. Newham and Waltham Forest are both boroughs where significant cuts have also been made as well as increases. In Sutton four out of seven packages received increases (of 19%, 63%, 28% and 24% respectively), one package is currently being reviewed, one resident moved out of borough and another passed away.



London Borough	Number of former ILF recipients resident	Percentage of support packages that have been reduced
City of London	1	0%
Enfield	No answer	0%
Hammersmith & Fulham	48	0%
Islington	78	0%
Kingston-upon-Thames	10	0%
Southwark	15	0%
Sutton	7	0%
Tower Hamlets	27	0%
Wandsworth	15	0%
Westminster	21	0%
Ealing	42	2%
Haringey	48	2%
Barking/Dagenham	36	3%
Croydon	65	3%
Harrow	26	4%
Redbridge	50	4%
Lambeth	38	5%
Camden	50	8%
Hackney	54	9%
Brent	63	11%
Greenwich	56	11%
Hillingdon	34	12%
Richmond	25	16%
Bromley	42	19%
Barnet	89	29%
Lewisham	22	36%
Merton	19	42%
Havering	39	51%
Newham	43	56%
Hounslow	44	59%
Waltham Forest	60	68%
Bexley	33	Yet to reassess – 3 out of 4 done at time of FOI stayed the same, one reduced due to misuse of funds
Kensington/Chelsea	30	Info not held

## 6.5 QUESTION 3

**The government has committed to four years' worth of funding through the former ILF Recipient Grant. Will your London borough be:**

- **Ring-fencing this to care and support for former ILF recipients?**
- **Ring-fencing to adult social care?**
- **Not ring-fencing?**

6.5.1 Six boroughs reported that they will be ring-fencing the Former ILF Recipient grant from central government to support for former ILF recipients (Enfield, Hackney, Hammersmith/Fulham, Harrow, Islington and Wandsworth). 18 boroughs said they will be ring-fencing funds from the grant to the Adult Social Care budget while five said there will be no ring-fence in operation (Barking/Dagenham, Brent, Bromley, Hounslow, Waltham Forest). Five boroughs either did not answer this question or said they do not have this information.

## 6.6 QUESTION 4

**How many former ILF recipients have as part of their re-assessment been referred for a Continuing Healthcare Assessment, and of these how many were found eligible?**

6.6.1 18 boroughs reported that they had referred former ILF recipients for Continuing Healthcare (CHC) as part of the reassessment process. Of these 12 had referred less than five cases (Hillingdon and Hounslow), two had referred less than 10 (Brent and Kensington/Chelsea) and four had referred less than twenty-five (Brent, Hackney, Lewisham and Newham). Of the total number of cases referred for a CHC assessment less than two thirds were eligible (68 out of 114). Some boroughs had a high number of ineligible referrals: of the 19 referred by Newham only two were found eligible and of the 12 by Brent only three. Less than half of those referred by both Hillingdon and Hounslow were found eligible.

6.6.2 Two boroughs (Camden and Haringey) volunteered information about systems for screening for eligibility before referring for CHC assessments. There were no ineligible referrals reported by either of these Local Authorities.

## 6.7 QUESTION 5

**How many complaints have been received from former ILF recipients concerning their re-assessments and the outcomes thereof?**

6.7.1 Omitting Barnet who did not specify an exact number (they reported that "less than five" complaints had been received), a total of 43 complaints were received by London boroughs in response to their handling of transfer from the ILF. Nearly half of these (19) were directed at one single Local Authority (Waltham Forest). Boroughs reporting higher numbers of complaints correspond to those boroughs with the highest percentages of cuts to support packages: Havering reported five and Greenwich three.

## 6.8 QUESTION 6

### How many former ILF recipients have been moved into residential care following the closure of the ILF?

- 6.8.1 Four boroughs reported that former ILF recipients had moved into residential care following closure of the ILF. The majority of these were apparently unrelated to the transfer to local authority support: Harrow were keen to stress that the one individual in their borough who had moved to residential care had done so of their own volition and that no capping of support costs to live in the community had taken place, one individual in Sutton was discharged from hospital into nursing care before passing away and two in Merton were also apparently not connected to the ILF closure (one followed a safeguarding issue and the other a breakdown in a relationship). There was no explanation from Brent concerning the two individuals in their borough.

## 6.9 ANALYSIS

- 6.9.1 The overwhelming conclusion to be drawn from the FOI responses is the extent to which a dramatic post code lottery operates across London for former ILF recipients. While a number of Councils have made a decision to maintain pre-ILF closure levels of support, others have made substantial cuts suggestive of a systematic approach of 'levelling down' packages. By naming the further four years of funding the 'Former ILF Recipient grant', central government has conveyed a clear intention that the funds should be used for the specific purpose of supporting former ILF recipients. However, as with the 2015-2016 Transition grant, the funding has not been ring-fenced as a condition of draw down and a number of LAs have clearly taken a decision not to take on responsibility for replacing support previously provided by the ILF.
- 6.9.2 Two of the five boroughs not operating a ring-fence (Hounslow and Waltham Forest) have the highest percentage of reductions across London. Taking a systematic approach to reducing packages is inconsistent with LA responsibilities as set out in the Care Act to take a personalised approach where the needs and wishes of the Disabled person should be at the centre of any assessment. It also results in higher numbers of complaints against the LA that need to be investigated. Where these involve threats of legal action and require reassessments to be carried out there will be a significant resource implication.
- 6.9.3 Another clear finding from analysis of the FOIs is the amount of time that has been wasted through ineligible referrals for Continuing Healthcare (CHC) funding. In one borough (Newham) only two out of 19 referrals were reported to have been found eligible for CHC while in another (Brent) only one quarter of the twelve referrals resulted in CHC funding.
- 6.9.4 The FOIs provide little or no evidence of enforced moves into residential care as a result of the closure of the ILF. This is a real fear among Disabled people with high support needs. Anecdotal evidence reveals that social care users are already

being threatened with this by social workers while a number of authorities outside London, for example Bedfordshire, are beginning to impose caps on support costs to live in the community. To date no London borough has to our knowledge attempted this.

## CASE STUDY

My appointed assessor / Social Worker completed the RAS, and did this using the information I gave her. No arguments or quibbles about anything at all, she's backed me 100%. I maxed out my answers re. points to every question I could. There was one question I scored "0" on and there's nothing I can do about it as it relates to caring for others - I'm not caring for a child, elderly relative etc. Though. Hence I scored 86/100 points - the missing 14 all relate to the final question. I asked to see the conversion table, happily provided so I've seen the evidence. This came to £502 - yes that's crap. They are allowed to put a discretionary amount at RAS stage up to 15%, this was done immediately taking it to £572, which is still well short of what I need. I do think my social worker is very much on my side but what can the Local Authority do when what I got through the ILF is so much higher than their cap? As a disabled person in employment in the teaching profession a lack of support will directly impact on my ability to remain in work.

Following a period of stalemate and desperate appeals to my MP, it took a change of assessor, a senior person, to start making some progress, together with the all-too-late statement and funding transfer by the government of former ILF monies.

I have now, in cash terms, been restored to my prior level of ILF funding. However, it must be noted that the last inflation-linked increase I had was in 2011. Hence, in real terms, my funding has fallen, against a further backdrop of significant increases in the national minimum / living wage and future costs in terms of pension funding commitments. So, whilst better than the earlier catastrophic situation above, my difficulties with respect to funding an adequate level of staff to maintain a working support package remain.

In further respect of my work and life, the ongoing impact and stress of continual assessment, re-assessment, having to fight for basic things, has been a major contributor in my dropping out of the workforce, at least temporarily, in order to take a career break.

## 7. London Deaf & Disabled People's Organisations' Survey

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7.1 14 organisations (11 borough specific and three pan-London) returned completed surveys and one other submitted detailed information in freeform text. The majority (8 out of 12) wished to remain anonymous.

### 7.2 FINDINGS

7.2.1 Two thirds of respondents who answered this question (8 out of 12) reported a negative experience of transition management by their LA. Two DDPOs gave their LA a positive score while one did not know and another reported no impact either way.

“Most of the people we had contact with were not offered advocacy or made aware of their rights during the process. The process could have been much better if the people assessing former ILF users were aware of the proper procedures they needed to go through and the fact that the Council was still receiving money from Central Government for previous ILF users.”

“it was a mess from start to finish, with very poor communication with users, transfer processes that involves flawed assessments, and in some cases bullying of disabled people or family carers.”

“assessments should have all taken place by 29 Feb 2016 for ILF users (based on court order) but that hasn't been the case; ILF transition reports don't appear to be taken into account in assessments; the approach to assessments is inconsistent with some people getting a full care act assessment and others getting a print out of a previous (non-care act) assessment and being asked to comment on it; assessments are too short (1 hour) resulting in lots of follow up queries, which are then taking place without an advocate or there are further delays while an advocate is re-booked; inconsistent approach to sharing draft reports with some assessors sharing them and getting feedback, others send it straight to panel with no input; power imbalance between some assessors who are making recommendations against the wishes of the individual and not adequately taking their needs and how to live independently into account; long delays getting to panel and long delays getting the result from panel ... very poor communication by assessors on the process and timescales.”

“In many cases ex ILF users were informing the LA of how the transition should be managed and educating them on independent living issues.” DDPO

“Social workers in our local authority have been going round telling people the amount of funding being transferred from central government is only 40% of the ILF budget so cuts have to be made.” DDPO

- 7.3 Half of respondents did not know what plans their LA has for the Former ILF Recipient grant monies. Three reported that their LA was planning to ring fence funds to former ILF recipients, two said their LAs were going to ring-fence to Adult Social Care and another reported that no ring-fence was planned.

“I have emailed the Council and spoken to them in person about whether the money is ring-fenced and got conflicting answers from different people in senior management.”

“political decision to ring-fence until 2018” [NB this decision was taken before the government announced its consultation on the Former ILF recipient grant]

“refusal by council officers to recommend to councillors to ring-fence the additional years of funding. . .It is even possible that the LA will transfer that money to another department, or reserves, as it hasn't previously been budgeted for.”

“Even those boroughs which have ring-fenced the monies seem to be treating the ILF part differently by not offering incremental/cost of living rises on that part and having a different set of rules for that funding.”

- 7.4 More than two thirds of respondents rated the impact of the closure of the ILF on their members who are former recipients as negative. Four DDPOs reported no impact and these mainly correlated with those who scored their LAs positively for transition management.

“We have one member whose physical health has been adversely affected by the process. She has had to be hospitalised and is suffering more seizures due to the stress created from the potential loss to funding and independence. It has also impacted on two other users who were very upset by the way they were treated, but are so frightened about losing their funding that they will not speak up about it.”

“People have expressed significant worry and fear. It is felt that the LA has pre-determined the funds available and people's needs will not be met as there is not enough money to go round. One person has had a stroke during the process and others have expressed concerns around their mental health. The experience of being assessed has been described as invasive and as an organisation we're very concerned about the impact on people's mental health due to the way the assessments are being done and the poor process surrounding them, in addition to the longer term impact of less support being available (for some).”

“stress and mental health problems”

7.5 The survey asked whether DDPOs had noticed any impact on other social care users who had not received support from the ILF. Nearly half (6 out of 12) responded that they did not know and three reported no impact. The remaining five scored a negative impact. Their answers were linked to the fact that alongside the closure of the ILF, the need to make budget savings is leading to cuts that affect all social care service users.

“[Our] Council will be making a further savings of more than £50 million over the next 4 years. Sadly Social care will be affected by these funding cuts.”

“The transition money is being swallowed up by the cuts overall. 10% of the adult social care budget is being cut in 2016-17, on top of very high cuts over the previous few years, and more planned in the years to come.”

“the Council has continued to make cuts to care packages, in spite of having raised a 2% precept on Council tax ring fenced for social care. there is even pressure to reduce the support to people with high support needs on 24 hour care packages, who were not funded by the ILF - this would put them at serious physical risk. the average amount of support awarded to our clients has decreased substantially over the past 2-3 years.”

“Councillors voted not to apply the 2% council tax precept despite enormous cuts to services and are one of the few boroughs to take this approach.”

7.6 Ten DDPOs said that the closure of the ILF had had a direct negative impact on their organisation. Reasons cited for this were increased workload without additional funding, an increase in enquiries and extra stress on staff. This was true even in those areas rating their LA’s handling of the transition process as positive and where funding has been ring-fenced to former ILF recipients. The remaining four reported no impact.

“..we needed to campaign to protest what was already there.”

“Increase in number of enquiries.”

“We have had to spend more time supporting distressed users with our limited resources.”

“There has been an impact on staff who have found the processes difficult to navigate and draining, there has also been a peak of workload because all the assessments were bunched together by the LA and that means that inevitably some people will have been assessed without an advocate because we didn’t have capacity to provide one;”

“When [issues have] arisen we have had to pick this piece of work up.”

“The closure also had a direct impact because our Director was an ILF user and lost part of her support package.”

“Worry has caused [members] not to want to engage [in our activities] because of the uncertainty of support they will get to come to events.”

- 7.6.1 Two DDPOs volunteered information that their LA had underspent in their social care budget in the previous financial year. Both DDPOs felt that this was wrong in a climate where cuts were being made to essential support for Disabled people.

“I believe this has been another year where there has been an UNDER spend on the social care budget. In general, people’s allocated hours/budgets seem to be very low.”

“[The] Care services portfolio budget monitoring 2015/ 16 from 10th March 2016 reported the following underspend. ‘Overall the position for Adult Social Care is a predicted £745k underspend.’”

## **7.7 ANALYSIS**

- 7.7.1 The fact that so many DDPOs wished to remain anonymous indicates a fear of repercussions from speaking out negatively about their local Councils.
- 7.7.2 The relatively high number of DDPOs unaware of their Council’s position on ring-fencing the Former ILF Recipient grant reflects either a lack of decision or poor communication from a number of LAs. Such uncertainty causes anxiety and distress to former ILF recipients awaiting decisions upon which their futures depend.
- 7.7.3 The existence of a postcode lottery is demonstrated by the divergent experiences between different boroughs, with some DDPOs scoring their LAs as managing transition positively with no impact on former ILF recipients and others reporting negative management and negative impact.
- 7.7.4 While most DDPOs reported a negative impact of closure on former ILF recipients, none pointed to a corresponding positive impact on other social care users which could have occurred from an evening out of resources between those who previously had support through the ILF and those that did not. The negative impacts on DDPOs as a direct result of the closure of the ILF reflect the additional burden on resources that has occurred.



## CASE STUDY

“I don't have the written outcome of the reassessment yet but verbally I've been told the recommendation is that I receive 3 hrs per day 1 hr each morning to get me up, 1hr at lunchtime and 1hr to put me to bed at night. I have been told that I be provided with incontinence pads to help me to 'be more independent' through not being dependent on carers to take me to the toilet & assist me with toileting!

I currently get 5 hrs per day from Direct Payments/ Social Services and 7 hours per day from ILF totalling 12 hrs per day! I actually need & have someone with me almost 24 hours a day - the remaining unfunded hours provided by friends, neighbours and family and on a voluntary basis by my paid carers who know I cannot pay them for all the hours they put in! I have no idea when this recommendation will start to be enforced, I am guessing from 1st July when the ILF funding ceases. I was not expecting this to happen & have not given my carers any redundancy notice!

My assessment by the social worker was traumatic, embarrassing and dehumanising and being told my care recommendation is just three hours a day when I need someone with me 24 hours a day has left me stricken & panicked and fearful about how I am supposed to manage! I cannot stop crying & worrying & being overwhelmed by enormous levels of anxiety & stress & anger and I feel so bad for my carers too! They have been so dedicated to looking after & supporting me for so many, many years, putting in paid & unpaid hours to make sure I was safe & cared for at all times. One of my carers is a single mum and I am worrying about her in particular, as this will impact enormously, devastatingly on both her & her daughter & I feel it is my fault, my responsibility! Had I known sooner I could have given her redundancy notice & she could have been looking for additional work or how to sign on etc.

My current level of care support helps me be safe but also enables me to utilise my skills & experience and to participate & contribute meaningfully to society: I have served as Chair for three separate Disability charities, saving them from closure, moving premises & securing ongoing security & funding; have been involved in campaigning for Disability rights, equality & inclusion, and for Peace, for the Environment and a better more inclusive world for all of Life. If I am left in Incontinence pads day & night my already very vulnerable skin will be put at even greater risk resulting in breakdown, pain, infections & sores. If I am left without the care I need I will be at risk of more falls, dislocations & hospitalisation. If I am left without care I will not be able to reach or take my emergency medication when I experience episodes of muscle spasms which paralyse me with pain, so I need a carer to open and administer a dose orally and hold a glass so I can drink some water afterwards and to help to alleviate and distract me from the excruciating pain. If I am left without the care I need I will be housebound & even bedbound making my depression, stress anxiety & social exclusion unbearable.”

– Former ILF recipient

## 8. Emerging themes

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8.1 The following themes have been identified through comparison of the Freedom Of Information (FOI) responses, Deaf and Disabled People's Organisations (DDPO) survey, and examples of lived experience submitted by former ILF recipients.

### 8.2 POSTCODE LOTTERY

8.2.1 One of the reasons posited in favour of merging the ILF with mainstream care and support was the variation in take up of the ILF across different local authorities<sup>44</sup>. Since the closure of the ILF a bigger postcode lottery for former ILF recipients exists than ever before. In some areas support packages have to date remained unchanged while in others Disabled people with similar needs have experienced major cuts.

8.2.2 Rather than being needs-led, decisions on funding for individual support packages are tied to decisions on budget policy: whether or not to ring-fence the ILF grant monies but also the amount of savings allocated by local authorities to their social care budgets.

“They have reviewed all of the clients receiving ILF and as far as we are aware – clients have kept the same level of support.” DDPO

“...there doesn't appear to be any major changes to the level of support being made available, following reviews.” DDPO

“We still have not heard anything at all with regards a reassessment from our LA and the funding at the moment remains the same, so are keeping our heads down. I've spoken with another family who were on ILF too and the same applies to them”. Family member of former ILF recipient

“I actually ended up with a small increase from my reassessment. If I lived across the road I would be in the neighbouring borough and then it would have gone the other way. I count myself very lucky but I know other people aren't so fortunate.” Former ILF recipient

“In one borough an individual has been reassessed from 24/7 to 5 hours per day despite clearly having a care assessment from the local authority stating she needs 24/7 when she was in receipt of ILF. Her borough has not ring-fenced the second wave of funding for ILF recipients.” DDPO

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44. M Henwood, B Hudson, Review of the Independent Living Funds, Department for Work and Pensions, 2007.

“Re-assessment of ILF users by the local authority seems ill-informed and set on making reductions from budgets. A number of people were told they may need to move to care homes in order to meet their care needs or threatened with huge reductions to their budgets during the assessment.” DDPO

“Some evidence that recommendations made by social workers following the assessment are financially motivated rather than based on need, for example, one assessor wants to remove overnight support for an individual which is not justified by the evidence;” DDPO

“In the 2015-19 business plan the LA made it clear that every service user’s package was targeted for cuts, for example, “high cost learning disability packages” were to be cut by 6% while people with “Physical disabilities” receiving direct payments were to have their packages reduced by 10% in 2016-17. Older people, mental health service users, etc are all allocated their own level of cuts to support packages.” DDPO

“The Assistant Director of Adult Services told me that when the ILF closed that was the end of the support component previously covered by the fund. He said it was a government decision and nothing to do with the Local Authority that the support had ended.” DDPO

“My package of care is also made up of direct payments from the LA who have been quite unorganised and threatening towards me. Before we had confirmation that WILG [the Welsh Independent Living Grant] would carry on past March 2016 my social worker visited and scared me by stating that without WILG my hours of care would reduce from 86.5 to just 32 per week. As I have a progressive disability this is particularly scary as I need more hours now - not less.” Former ILF recipient in Wales

"...after a long drawn out process lasting many months my Council agreed to take over payment of my 24 hour care package."

## LOCAL AUTHORITY CASE STUDY: WESTMINSTER

“The ILF customers funding was passed to the council and this enabled us to protect packages by using the support money from central government. Support packages have therefore remained as they were.

This group have always been subject to support reviews and this will be done annually by the council to ensure packages are meeting needs correctly.”

## 8.3 NEGATIVE IMPACT

8.3.1 Despite the efforts put in by the ILF before closure to smooth the transition period and mitigate negative impacts on former ILF recipients, the experience of transfer has frequently been distressing. This is for a number of reasons including poor communication from the local authority, lengthy and frustrating assessment processes and the very real experience of having cuts made to essential day to day support. The impacts do not only apply to ILF recipients but extend to their families and the Personal Assistants they employ whose jobs are at risk.

“My experience was very stressful as [the Council] did not communicate with ILF recipients about the transition until early June 2015. Leaving ILF service users with the knowledge that the ILF would close on 30 June but no idea what would happen after this date... Myself and my staff found this time highly stressful. I had a very rushed meeting with a Care manger that had never dealt with the ILF and were very new to the Care Act, which meant I knew more about it than she did.”  
Former ILF recipient

“We got not a single piece of written information from the local authority prior to the closure of the ILF, not even to tell us we would be re-assessed- All the information came from the ILF.” Former ILF recipient

“the long and drawn-out process I am now going [through] for basic support, when all I want to do is get in with my life... not knowing what will/might happen is a terrible way to life your life” Former ILF recipient

“I do not know what other information they want or indeed how they have decided such a cut in my support plan.” Former ILF recipient

“I don’t know if my local authority has ring fenced the ILF money for this year.”  
Former ILF recipient

“The whole process including challenging the drastic cuts to my package with the support of a solicitor led me to have a nervous breakdown resulting in me being off work and on anti-depressants. Thankfully, nearly a year later, I’ve improved a bit but I’m only just beginning a phased return to work”  
Former ILF recipient

“We have seen the ways that the closure of the ILF has impacted on disabled people, causing stress, anxiety and increasing illness. The process has been handled very badly with little or no support for many. In addition, people have had packages cut in some instances by 90%.” DDPO

“Since a random phone call saying there was a cut to my package I’ve heard NOTHING from any social worker. I haven’t even seen my review of had any correspondence for months now.” Former ILF recipient.

“The assessment does not give a clear and more importantly accurate account of my daily care needs. There are items in it that are astoundingly wrong. This has caused me a level of distress that I am now concerned about as it is affecting my physical and emotional wellbeing. I have not wanted to eat for a couple of days and my mother had to cancel plans to come and be with me on Friday. This is not normal behaviour for me. I am a well-balanced and calm person. I have never felt like this during any assessments [previously] and truly feel this assessment has not been dealt with, with the skills needed to understand my complex disability and physical needs.” Former ILF recipient

“After two hours I said this is taking an age! Why is this taking so long the ILF assessors usually take no more than an hour? ...After a further two hours I said I have had enough! (a total of 4 hours)... [The triage social worker] said he would need to visit again. Which he did the following week for another lengthy meeting from memory again it was four hours could have been there. During this process he was asking such personal invasive questions such as how many pads do I use because I have “urge” incontinence. How many times do I use my washing machine? I then had to explain I mainly use chair or bed pads because it is easier that pads dig in causing pain in my bottom. That the NHS do not fund chair or bed pads they will only fund ordinary “pads” (three a day). He really should know this information. As you can imagine I found this all very distressing indeed I found myself crying and unable to speak. At no stage did the triage social worker say let’s have a break I have enough information.” Former ILF recipient

“I had an assessment on the 14th August 2014 by the Independent Living Fund. A social worker from my local authority was also meant to attend the meeting but never arrived. I received my assessment report and outcome 3 weeks later it remained exactly the same as it has been for over a decade which is £330.25 per week for 52 weeks per year. ...[After reassessment the LA] said I had been offered £179 per week support! This equates to £716 per month ~ a staggering reduction of £604 per month. As you can imagine I was and am stunned and totally shocked and upset!” Former ILF recipient

“I was told that I would be getting 10 hours a week less for my basic needs than I have been getting from the local authority for the past 17 years. I haven’t changed, in fact my needs are greater than they were. From an ILF package of average ten hours a day, I was allocated 3 hours a day- an hour in the morning (it takes me two hours, I get short of breath and sick if I do things too quickly), two half hours in the day and an hour in the evening. No support for food preparation, cooking, cleaning, shopping, laundry, driving and assisting me with essential appointments (including health ones as without support I can’t maintain my health), communicating for me when my hearing is poor, helping me to swimming to keep mobile, seeing family and friends, leisure or hobbies, let alone being part of the community. Again, I was not expecting the local authority to pick up all my ILF hours. Just to provide the basics.” Former ILF recipient

“So I had my annual care review yesterday from my local Adult Social Services and the council have told me that they are looking to cut back on my care package and want to remove the 24h live in care that I receive. The option is there to appeal if they make the cut but I’m told they no longer fund social care which I believe makes up 50+60% of my care package. At my review I clearly got upset and said to her so what am I meant to do about using the toilet during the day if I don’t have the care I need in place. She kept saying it’s not an issue that I can use ‘adult pads’ that they can provide from the council. She also said everything I need to live is in the 4 walls of my house. So pretty much by their logic I have no reasons to need to go out despite the fact I work/volunteer and have an active social life. I questioned the fact that I cannot prepare my meals and she informed me that the council can provide (at a cost to me) either some meal delivery service or I can service on microwave meals (Which again I cannot physically use). So the care the council want to put in place is 3 visits a day from an agency. 1 to get me up in the morning, another to change this ‘adult pad’ during the day and another to put me to bed. Personally I find this very demoralising, appalling and inhumane...! Its also worth mentioning that nearly 2 years ago an application was made to the NHS for support with my care funding as my health is getting worse and is requiring more of a ‘medical’ package. I called them yesterday for an update and turns out they’ve lost my file, it’s no longer on system and iv been told to start application process again. Which is a 6-18 month decision turn around. Can’t help but feel that I’ve been left neglected by adult social care and the NHS. I don’t have any family to support me. It’s just me, myself and I.” Former ILF recipient

"My Council won't pay for support with domestic tasks like cleaning or dusting. I have no family and friends who can do it for me. Surely living in dirty conditions is a health issue? They also won't give me enough money to pay the National Minimum Wage for over-night support. I would describe this whole process as abusive and I used to be a social worker. It has been going on since April and suddenly I receive a letter dated 18th August but not reaching me until a week later, telling me I need to obtain and send in complex up-to-date medical evidence by 2nd September. I am tetraplegic, my condition is not going to change and they have all the medical evidence already on file. They are also insisting I have an OT assessment and say they are consulting with "spinal injury specialists" on equipment that could be used to turn people in the night so we won't need overnight support. They are looking at every avenue to make cuts." Former ILF recipient.

## LOCAL AUTHORITY CASE STUDY: HARINGEY

“All ILF recipients were screened for CHC as part of their reassessment. None met the criteria for health funding.”

## 8.4 CONTINUING HEALTHCARE (CHC) REFERRALS

- 8.4.1 There is a clear lack of consistent practice across different LAs with regard to referrals for CHC funding. Whereas some boroughs have made a high number of ineligible referrals others operate a screening system. This would seem to an eminently sensible approach and one that would be beneficial to share across all London boroughs.
- 8.4.2 The application process for CHC funding is lengthy, the assessments can take many hours and can be distressing for the individual involved. Due to the nature of the funding assessment questions are extremely intrusive, covering in detail issues including continence, altered states of consciousness and inappropriate behaviours such as indecent exposure.
- 8.4.3 CHC assessments are not something that Disabled people, already anxious as they await decisions over the futures, should be put through lightly, and yet some boroughs appear to have made CHC referrals as a routine part of their post-ILF reassessment process.

“Once we were outside the CHC assessor told me that her time is currently being ‘misappropriated’ by Councils making ineligible referrals trying to get health to take over funding for people who used to be on the ILF.” DDPO

“There has been a noticeable increase in people being assessed for continuing care when it is obvious that they are not eligible – this is unfair as people are being led to believe that this will fund them, only to be turned down. Continuing care assessments by their very nature are medicalised and focus on what a person cannot do and can be quite distressing, it is not acceptable to put people through these assessments when it is obvious they will not receive funding.” DDPO

“My experience is of the disabled person saying to me that their social worker is applying for CHC funding and they are happy as they assume this will mean more money and when I say I don’t think they will be eligible they are confused.” DDPO

“The process to get CHC funding is slow and painful and results in massive stresses to the disabled person as everyone jumps through hoops to meet the criteria. I know of 2 cases that have taken over a year to establish.” DDPO

### LOCAL AUTHORITY CASE STUDY: CAMDEN

“The Council’s Care Act Assessment process checks all people who are assessed for potential CHC assessment and where a threshold is met, they are referred for CHC assessment.”

## 8.5 LIMITATIONS OF THE MAINSTREAM CARE AND SUPPORT SYSTEM

8.5.1 A strong theme emerging from the lived experience of former ILF recipients is the limitations of LA administered social care support. The ILF was never perfect but it did compare more favourably than mainstream care and support in areas such as the skills and knowledge of assessors, the accuracy and transparency of assessment processes, flexibility and choice and control, more manageable monitoring and fewer errors. In particular, ILF assessors appear to have had a much better grasp of the employment obligations of Direct Payment users employing Personal Assistants and the hourly rates paid by ILF recipients were often higher than their LA blanket rate. An additional issue is the high staff turnover in adult social care departments.

“In summary, there are significant issues with the support, processes and funding for all community care users, and additional problems on top of these faced by ILF users.” DDPO

“..too often clients are reporting they never received a copy of the assessment/reviews and were never told what their budget is.” DDPO

“Disabled people are getting support within the home i.e. washing, toileting/dressing – i.e. getting up and going to bed/personal care and support with meals, if needed. This level of support can suit some people such as older Disabled people who do not wish to go out outside the home... However, it is much more difficult to obtain support for activities outside the home,” DDPO

“The size of personal budgets do not enable Disabled people to employ a personal assistant because there are too few hours employment in one day to may it feasible for the PA.” DDPO

“Control by LAs means restrictions and inadequate support. This was true under the system before with the ILF as a result of LA involvement. I was only given support for 4 nights a week. Last year I was ill and vomited repeatedly through the night for a number of nights when no one was present. I had to lie in that and could so easily have choked to death. This was and is the case due to the LA’s involvement.” Former ILF recipient

“The social worker then went on sick leave, then mysteriously left! Last October I was called for a review, seen by a social worker I didn’t know who said “I’m not looking to cut your package”. I said thank you will I see you next year to which she said - no I’m leaving next week.” Former ILF recipient

“I know they will have spent a considerable amount of money on recruiting and employing new staff on temporary contracts to assess us... nearly all of them... left – probably in disgust at the way they were having to act as accountants.” Former ILF recipient



“Cuts to staffing have resulted in shambolic service delivery with experienced staff leaving, locums, vacant posts and large numbers off sick. This has resulted in people having very delayed assessments, often with social workers who don’t know them and aren’t experienced. This results in poorly done assessments and recommendations made by social workers which are not supported by the evidence of people’s needs;” DDPO

“In one case we advocated for the social worker arranged to meet the Disabled people. We all thought it was to go through the list of accuracies we had highlighted in the reassessment report. It turned out the reassessment report had already gone to the funding panel, without having been corrected, and the social worker was there to announce a dramatic cut in support hours to take effect four weeks to the day, not leaving enough time for notice periods for the person’s longer serving Personal Assistants.” DDPO

“The assessment said the individual had “declined the offer” of a commode but said nothing about the reason for this - the reason being that without support she couldn’t transfer onto the commode so it would have been absolutely no use during the hours they were proposing she had no longer had support for.” DDPO

“not understanding the detail of employing a PA and issues around payroll services... With better policies in place this could and should have been avoided.” DDPO

“For someone like myself I have employed my PA for 7 years plus, as an employer I am responsible for giving 7 weeks’ notice to my PA of any changes to her pay or hours.” Former ILF recipient

“In theory my hours are remaining the same but they are reducing the hourly rate to a flat rate of £8 (previously we have daytime weekday, daytime weekend, evening weekday and evening weekend.” Former ILF recipient

“no recognition from the LA on the employment implications for people who have employed staff on the ILF fund rate and now the LA’s direct payments rate is lower and packages are being calculated on that basis rather than recognising that existing staff need to be kept on and you can’t just cut pay; failure by the LA to incorporate pension costs into personal budgets or to implement any pay increases even though pay has been frozen for over 5 years;” DDPO

“One borough is paying the direct payment part at the London Living Wage but the ILF part at the national living wage.” DDPO

“The...issue is what the funds have been spent on and how they fit into the council’s eligibility criteria.” DDPO

“ACAS now define work as anytime when someone is present and available to work, as working - which means that my LA are acting illegally, by only funding sleeping rate at so much less, which doesn't seem to bother them! So basically, I have had to increase my wages, but I am not getting any more funding.” Former ILF recipient

“I'm trying to get increase in hourly rate to pay the statutory Living Wage (LW) plus an increase for PAs. I'm paying a little above LW but it's far too low. My area has one of the lowest rates. It's difficult to compete with other employers of support workers.” Former ILF recipient

“In my ILF assessment it says about how I manage my direct payment and how flexible that package needs to be because of my fluctuating various impairments. I feel like they are trying to fit a square peg in a round hole! The assessment isn't fit for purpose.” Former ILF recipient

“I live independently in the community with support. I don't have any relatives alive who live close to me ... My life is complicated and lumpy at times but I manage very well with the current support I have. If any part of my system breaks down I will be in desperate trouble. It is a very finite system that works well for me as it should be. I have a bank overdraft to cover for payments when I do not have enough money to pay enablers then the overdraft is cleared once the following months money comes in because I may well have used more hours than is catered for in one month. I won't be able to do this if my support package shrinks so much I do not know what tomorrow will bring I can plan but things change day to day week to week.” Former ILF recipient

“I have 24/7 care in my own home, I manage my finances myself and the payroll via the HMRC website. Historically I was on the higher rate of the Independent living fund and also I have the earlier version of independent living fund being on their books since 1993. This had plateaued out at their maximum rate they could give me, the other monies came from my care package entitlements from the local authority and because I was on the higher rate of mobility allowance part of my monies went into the pot to pay my carers. Because the package was at their maximum, my carers had not had a raise in finances for the past six years. After the ILF shut and the LA took over responsibility for paying all my support costs I noticed extra money in my account. I assumed this was as a result of the transfer. My first thought was to use it to give my PAs a pay rise – because they deserve it but also because it would have a devastating impact on my life if I were to lose PAs with the skills and experience they have built up. My LA has just contacted me to tell me it was a mistake and I need to pay back the extra money over the past few months. I simply don't have that money and the only way I could pay it back would be to cut my support hours which I need.” Former ILF recipient

“I have found [Council] monitoring every 3 months is a lot stricter and they have requested a lot more information on expenditure than I have ever had to submit before. I have also had to explain why I have a surplus of monies in my account when banking hours for an operation... despite giving an explanation on the monitoring form, I was contacted by [Council] staff and a financial officer visited with me to discuss this further.” Former ILF recipient

“the detail of what information is required when monitoring has caused some worry and confusion.” DDPO

"I received a letter by recorded delivery which I had to sign for, demanding repayment of thousands of pounds from my direct payments budget... There were also errors in the letter... This indicated to me the staff had not read the covering letter I sent with the forms and invoices... It also only referred to one Care Plan, I had had two care reviews in the monitoring period over two years, yet the former care plan was never even mentioned... In emails I pointed at several times how stressed and harassed I felt, even abused but no one cared or responded adequately let alone initiated a Safeguarding process by at least involving my care manager or any care manager! So next I was then told I had to produce even more evidence as it had been such a long period of time... after I sent in extra evidence assured me the amount to be refunded would be much less... I then received an invoice in the post for the full amount again, this caused me again such upset and stress. I had to email staff again and was told this was an error and a further invoice would be sent.” Former ILF recipient

## **8.6 VALUE OF THE ILF**

### **8.6.1 What comes through strongly is the value placed on the ILF by Disabled people and their families as a source of independent living support that met the civil rights of recipients in a way that LA administered care and support does not.**

“[Under the LA] the decisions are under political control, [whereas] the ILF was needs based.” DDPO

“Whilst the ILF wasn’t perfect by any means, it was an awful lot better than what the future holds under Local Authority run care.” Family member of former ILF recipient

“I am seeing people receiving only the basic support to sustain them rather than an independent living support.” DDPO

“The ILF provided security for the future but now I cannot plan ahead too far as WILG [the Welsh Independent Living Grant] is only guaranteed until 2020 and Wales is still deciding on a system to replace it with.” Former ILF recipient in Wales

“..the closure of the ILF was a very sad day as the ILF was a fantastic model of personal budgets that worked well for disabled people. It provided the extra hours needed to, live independently, providing night time care (promoting dignity and control), be part of the community and provide much needed support hours for socialising, household chores which [LA] social care does NOT provide...This is a massive step backwards for disabled people and all we have fought for. The switch over from ILF being a national fund to local authorities also means disabled people are faced with a ‘post code lottery’ which is a real concern for many disabled people.” DDPO

“in spite of our best efforts as advocates, we can only get care packages for basic care needs. Previously people who met the threshold could get support for independent living through PAs to go out, go to classes or volunteer, do gardening, go swimming or to other leisure activity - this is now almost impossible to get even if it is for ‘therapeutic’ reasons. All of these activities help people regain their confidence and independence and engage with the world. There is very little support for disabled parents to e.g. spend time with their kids, take them to activities. Without ‘social’ support there is a real risk some clients will return to the perpetrator because they have such poor quality of life. There is pressure for people to have ‘carers’ coming in for half an hour each time, which is meaningless in terms of independent living. The closure of the ILF is directly placing disabled people at risk in many different ways, and the prevailing approach is one of meeting minimum needs.” DDPO

## **8.7 IMPORTANCE OF DEAF AND DISABLED PEOPLE’S ORGANISATIONS AND CAMPAIGNS**

- 8.7.1 There is evidence of the important role DDPOs and Disabled people led campaigns have played in improving the transfer process. One example of a positive outcome resulting directly from the closure of the ILF involves a Disabled person who was put in contact with her local DDPO who were offering support for former ILF recipients. She was able to disclose to them that she was living in abusive situation and they supported her to escape.

“The only meeting with ILF recipients was organised by us but attended by the Council” DDPO

“We got agreement from the council to better inform and support social workers, and we ran a workshop inviting all ex ilf recipients. The more recent reviews (2 we know of) for ex-ilf recipients appear to have been better managed and the persons holistic needs reviewed (not separating what was once ILF)” DDPO

“I honestly feel I cannot identify anything else that has been done well with the exception of the LA advising me that my local CIL are there to support me independently from the Council. Thankfully Merton Centre for Independent Living have been there throughout.” Former ILF recipient

“more positively, because the LA let people know about our service we were able to support some people who hadn’t been in touch with us before. In one case, the person made a disclosure of long-term abuse by their carer and this resulted in the carer being sacked and the individual being supported in respite while they work out next steps” DDPO

“Thank goodness for the ILF fighting fund set up by Disabled People Against Cuts to cover legal costs for people who aren’t eligible for legal aid. I have referred a number of people to it who couldn’t have challenged very unfair decisions without it. It’s not that these people have spare money or resources – far from it – but the changes in legal aid mean they would have no access to justice without the fighting fund and without really dedicated and kind public lawyers.” DDPO

“We are a London organisation but spend so much time answering enquiries from people who used to get the ILF from outside London who need advice and information on their rights. You can’t just tell them sorry, can’t help if they have nowhere else to turn and are about to lose daily support that is absolutely essential for any kind of quality of life.” DDPO

“DPAC has been supporting ILF users since before the closure, we have supported the court cases and individuals. Support has been developed through a dedicated email list, through in person support and via legal challenges which are ongoing. We have also paid for solicitors because so many are thwarted by the legal aid restrictions, in order to provide legal support when cuts to packages after the closure to ILF gave no support at all. As such DPAC have developed an ex ILF users peer support group without funds.” DDPO

## 9. Conclusion

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- 9.1 The closure of the Independent Living Fund represents a clear step backwards in independent living support for Disabled people.
- 9.2 According to Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, as quoted in article 1.19 of the Care Act 2014 Statutory Guidance, States such as the UK who are signed up to the Convention should:
- “recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
  - (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
  - (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”
- 9.3 Despite assurances to the contrary in the run up to June 2015, the closure of the ILF has directly resulted in the removal of support from Disabled people with high support needs. Where support packages have so far remained the same this is due to specific funding for the support of former ILF recipients from central government linked to both national and local lobbying and campaigning by Disabled People. Continued support in many areas is dependent upon the continuation of this grant funding.
- 9.4 The postcode lottery of support provision this research reveals is simply not acceptable. Disabled people’s independence, choice and control should not be dependent on the choices, compromises and dealings of local politicians. Disabled people need a national independent living support service that ensures consistent nationally applied levels of support that reflect and help make our rights under the UNCRPD a reality.
- 9.5 Likewise, the ability and competence of local authorities to implement the Care Act 2014 is highly questionable. Experiences of former ILF recipients going through reassessment reveal assessment processes that fail to put the Disabled person at the centre and funding decisions that remove choice and control.

- 9.6 The experience of former ILF recipients mirror those of adult social care users who missed out on or would not have been eligible for the ILF, for example limited support to leave the house, being expected to live off microwave meals to reduce hours needed for support with domestic tasks, and being labelled as difficult for presenting objections to the replacement of support with inappropriate telecare or incontinence pads.
- 9.7 The ILF was never perfect, with particular problems arising from the required involvement of LAs and tightening eligibility criteria as demand increased. However, the model of support which the ILF represented provided a level of independent living that LA administered social care has not only on the whole failed to but is also moving further from as the result of budget cuts.
- 9.8 It seems nonsensical that within the current climate, an effective system that supported Disabled people to contribute to society, including being able to gain skills for and take up employment, that not only worked but provided excellent value for money, should have been shut and its functions transferred to one that is in crisis and struggling to meet its most basic statutory obligations. As the mainstream care and support system fails, unable to implement the lessons learned from the ILF, Disabled people's rights and freedoms are being taken back decades.
- 9.9 The Care Act 2014 says many good things but lacks enforcement mechanisms so that it is up to individual Disabled people – those who face the biggest barriers in society – to hold LAs to account. Even where individuals have the rare confidence and support to challenge LA decisions and initiate legal action the changes to legal aid restrict the number of people for whom this is an option.
- 9.10 This report also shows the important role that Deaf and Disabled People's Organisations and peer support networks play in ensuring that Disabled people are aware of and have support to exercise their rights. At the same time ever decreasing funding is placing greater strain on DDPOs and facilitation for peer support forums is becoming a thing of the past.
- 9.11 There is an urgent need for a radical rethink of how Disabled people are supported to live independently. Disabled people who use independent living support must be at the forefront of developing ideas and with adequate resources for meaningful engagement.
- 9.12 This also needs to happen quickly, before the memories of what effective independent living support looks like and how much Disabled people can contribute when our support needs are met fade into the distance.

## 10. Recommendations

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1. To establish a national, needs-led system, independent of local authorities to administer independent living support, free at point of delivery and paid for through taxation. This system should build on the learning from the Independent Living Fund and be a key strategic mechanism for ensuring Disabled people's rights under the UNCRPD are fully and consistently realised across the country
2. For an independent living task force to be set up led by Disabled people and social care service users to be at the heart of developing ideas for the establishment of a national system.
3. For adequate investment in independent living support to enable Disabled people to have the support we need in all areas of our lives and to be able to recruit, employ and offer job security to Personal Assistants with the skills and experience required.
4. For adequate investment in high quality, fully accessible, community based independent living support services, including those run by DDPOs, to enable Disabled people to set up, manage and maintain their independent living support.
5. For research to be undertaken to evidence the business case for real investment in independent living support for Disabled people.
6. For an evaluation to be carried out into the impact of legal aid changes on Disabled people's access to justice and for remedies to be proposed to overcome the barriers that these changes have presented.
7. To urgently introduce national systems for monitoring Local Authorities with responsibilities for social care on their implementation of the Care Act including collecting comparative data on assessment processes, the types of support that are funded (eg domestic and social as well as personal care), hourly rates set by LAs, the range of options available to Direct Payment users for managing their budgets, and the impact of Council budget setting processes, and for there to be real consequences for LAs whose practice breaches statutory legislation.



8. For the Former ILF Recipient grant to be ring-fenced to ensure it is spent on meeting the support needs of former ILF recipients.
9. For a Former ILF recipient grant to continue to be paid to Local Authorities for every year until a national, independent social care system is operational, and for this grant to be paid by central government and not incorporated into the current proposals for self-sufficient local government.
10. To establish more effective systems for sharing good practice between different Local Authorities and Adult Social Service departments.
11. For Local Authorities to ensure staff working in adult services are properly trained in the Care Act 2014 but also in employment legislation relevant to individual employers.
12. Ensure Local Authorities employ sufficient social care staff with experience to carry out timely assessments and reviews and to ensure that Disabled people are involved throughout the decision making process.
13. To invest in the unique role and added-value of Deaf and Disabled People's Organisations in enabling and supporting independent living including a new target and matching resources to establish a DDPO in every Local Authority area and ensuring adequate funding to make our organisations sustainable.
14. For work to be undertaken, led by Disabled people, to raise the profile of employment as a Personal Assistant.

## Appendix A: Breakdown of ILF transition grants paid to English Local Authorities

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Local Authority	Total ILF commitment for 9 months
Barking & Dagenham Social Services	£385,507
Barnet Social Services	£1,165,779
Barnsley Social Services	£1,445,822
Bath & North East Somerset SSD	£369,819
Bedford Borough Council SSD	£292,949
Bexley Social Services	£540,533
Birmingham Social Services	£3,552,018
Blackburn with Darwen Borough Coun SSD	£335,640
Blackpool Borough Council SSD	£146,558
Bolton Social Services	£747,067
Bournemouth Borough Council SSD	£217,276
Bracknell Forest Council SSD	£215,571
Bradford Social Services	£1,632,674
Brent Social Services	£759,284
Brighton & Hove Borough Council SSD	£491,081
Bristol SSD	£1,407,399
Bromley Social Services	£526,049
Buckinghamshire County Council SSD	£891,008
Bury Social Services	£250,600
Calderdale Social Services	£691,201
Cambridgeshire County Council SSD	£1,037,438
Camden Social Services	£683,435
Central Bedfordshire Council SSD	£361,799
Cheshire East SSD	£748,654
Cheshire West & Chester SSD	£1,303,717
Cornwall Social Services	£2,254,498
Corporation of London Social Services	£6,277
Coventry Social Services	£2,020,637
Croydon Social Services	£835,261
Cumbria Social Services	£2,818,965
Darlington Borough Council SSD	£651,162
Derby City Council SSD	£927,939
Derbyshire County Council SSD	£2,204,184
Devon County Council SSD	£2,280,812

Local Authority	Total ILF commitment for 9 months
Doncaster Social Services	£593,191
Dorset County Council SSD	£604,278
Dudley Social Services	£880,057
Durham County Council SSD	£1,342,178
Ealing Social Services	£470,323
East Riding of Yorkshire SSD	£767,553
East Sussex County Council SSD	£831,544
Enfield Social Services	£631,142
Essex County Council SSD	£4,426,457
Gateshead Social Services	£337,340
Gloucestershire Social Services	£771,656
Greenwich Social Services	£941,307
Hackney Social Services	£616,718
Halton Borough Council SSD	£570,740
Hammersmith & Fulham Social Services	£671,292
Hampshire County Council SSD	£3,550,146
Haringey Social Services	£591,929
Harrow Social Services	£256,754
Hartlepool Borough Social Services	£506,623
Havering Social Services	£509,244
Herefordshire Council SSD	£1,024,226
Hertfordshire Social Services	£1,690,668
Hillingdon Social Services	£428,709
Hounslow Social Services	£427,537
Isle Of Wight Social Services	£129,591
Islington Social Services	£1,028,164
Kensington & Chelsea Social Services	£398,245
Kent County Council SSD	£1,669,726
Kingston upon Hull Social Services	£243,136
Kingston upon Thames Social Services	£140,408
Kirklees Social Services	£703,670
Knowsley Social Services	£821,902
Lambeth Social Services	£536,924
Lancashire County Council SSD	£4,797,786
Leeds Social Services	£517,913
Leicester City Council SSD	£727,553
Leicestershire County Council SSD	£1,010,640
Lewisham Social Services	£502,165
Lincolnshire Social Services	£1,386,424
Liverpool Social Services	£3,750,029
Luton Borough Council SSD	£357,135

Local Authority	Total ILF commitment for 9 months
Manchester Social Services	£1,725,395
Medway Council SSD	£626,637
Merton Social Services	£261,454
Middlesbrough Borough Social Services	£1,589,506
Milton Keynes Council SSD	£575,519
Newcastle Upon Tyne Social Services	£973,943
Newham Social Services	£508,922
Norfolk Social Services	£1,199,141
North East Lincolnshire District SSD	£149,550
North Lincolnshire District SSD	£472,721
North Somerset Social Services	£299,461
North Tyneside Social Services	£532,320
North Yorkshire County Council SSD	£1,189,190
Northamptonshire Social Services	£677,017
Northumberland Social Services	£731,108
Nottingham City Council SSD	£610,655
Nottinghamshire County Council SSD	£2,304,795
Oldham Social Services	£2,244,091
Oxfordshire Social Services	£3,003,715
Peterborough City Council SSD	£101,660
Plymouth City Council SSD	£506,314
Poole Borough Council SSD	£463,930
Portsmouth City Council SSD	£388,394
Reading Borough Council SSD	£204,346
Redbridge Social Services	£645,174
Redcar & Cleveland Borough SSD	£295,935
Richmond upon Thames Social Services	£334,103
Rochdale Social Services	£429,634
Rotherham Social Services	£1,253,857
Royal Boro' of Windsor & Maidenhead SSD	£97,995
Rutland County Council SSD	£53,618
Salford Social Services	£683,291
Sandwell Social Services	£891,834
Sefton Social Services	£1,832,183
Sheffield Social Services	£2,195,307
Shropshire County Council SSD	£1,315,002
Slough Borough Council SSD	£271,203
Solihull Social Services	£668,680
Somerset Social Services	£1,037,444
South Gloucestershire Council SSD	£722,350
South Tyneside Social Services	£241,848

Local Authority	Total ILF commitment for 9 months
Southampton City Council SSD	£349,083
Southend Borough Council SSD	£330,821
Southwark Social Services	£155,876
St Helens Social Services	£940,905
Staffordshire County Council SSD	£2,019,619
Stockport Social Services	£801,941
Stockton-on-Tees Borough SSD	£435,941
Stoke-on-Trent City Council SSD	£519,330
Suffolk Social Services	£2,021,086
Sunderland Social Services	£708,428
Surrey Social Services	£1,372,757
Sutton Social Services	£97,732
Swindon Borough Council SSD	£332,721
Tameside Social Services	£631,493
Telford & Wrekin Council SSD	£730,176
Thurrock Borough Council SSD	£253,182
Torbay Borough Council SSD	£373,047
Tower Hamlets Social Services	£333,927
Trafford Social Services	£314,262
Wakefield Social Services	£732,065
Walsall Social Services	£703,100
Waltham Forest Social Services	£955,686
Wandsworth Social Services	£220,868
Warrington Borough Council SSD	£458,314
Warwickshire Social Services	£1,523,570
West Berkshire Council SSD	£351,036
West Sussex Social Services	£3,747,646
Westminster Social Services	£258,069
Wigan Social Services	£1,266,509
Wiltshire County Council SSD	£940,280
Wirral Social Services	£1,324,947
Wokingham Council SSD	£230,456
Wolverhampton Social Services	£825,192
Worcestershire County Council SSD	£2,460,258
York Council Social Services	£289,814
<b>Total</b>	<b>£139,681,017</b>

## Appendix B: Breakdown of Former ILF Recipient grant funding by Local Authority area

Authority	2016-17	2017-18	2018-19	2019-20
Barking	£488,107	£472,034	£457,128	£443,242
Barnet	£1,476,044	£1,427,439	£1,382,360	£1,340,371
Barnsley	£1,830,619	£1,770,338	£1,714,431	£1,662,355
Bath	£468,244	£452,825	£438,525	£425,205
Bedford	£370,916	£358,702	£347,374	£336,823
Bexley	£684,392	£661,856	£640,954	£621,485
Birmingham	£4,497,367	£4,349,272	£4,211,923	£4,083,985
Blackburn	£424,968	£410,974	£397,996	£385,906
Blackpool	£185,564	£179,453	£173,786	£168,507
Bolton	£945,894	£914,747	£885,859	£858,951
Bournemouth	£275,103	£266,044	£257,642	£249,816
Bracknell	£272,943	£263,956	£255,620	£247,855
Bradford	£2,067,201	£1,999,130	£1,935,997	£1,877,191
Brent	£961,363	£929,706	£900,346	£872,997
Brighton & Hove	£621,780	£601,305	£582,316	£564,628
Bristol	£1,781,970	£1,723,291	£1,668,870	£1,618,178
Bromley	£666,054	£644,121	£623,780	£604,832
Buckinghamshire	£1,128,144	£1,090,995	£1,056,542	£1,024,449
Bury	£317,296	£306,847	£297,157	£288,131
Calderdale	£875,160	£846,341	£819,614	£794,718
Cambridgeshire	£1,313,546	£1,270,292	£1,230,176	£1,192,809
Camden	£865,327	£836,833	£810,406	£785,790
Central Bedfordshire	£458,090	£443,006	£429,016	£415,984
Cheshire East	£947,904	£916,690	£887,741	£860,776
Cheshire West	£1,650,693	£1,596,337	£1,545,925	£1,498,967
City of London	£7,948	£7,686	£7,443	£7,217
City of York	£366,946	£354,863	£343,656	£333,217
Cornwall	£2,854,519	£2,760,522	£2,673,345	£2,592,142
Coventry	£2,558,418	£2,474,171	£2,396,037	£2,323,257
Croydon	£1,057,560	£1,022,736	£990,438	£960,353
Cumbria	£3,569,217	£3,451,685	£3,342,681	£3,241,146
Darlington	£824,465	£797,316	£772,137	£748,683
Derby	£1,174,904	£1,136,215	£1,100,334	£1,066,911
Derbyshire	£2,790,815	£2,698,916	£2,613,684	£2,534,293
Devon	£2,887,837	£2,792,743	£2,704,548	£2,622,397
Doncaster	£751,065	£726,333	£703,395	£682,030
Dorset	£765,103	£739,908	£716,542	£694,777
Dudley	£1,114,278	£1,077,586	£1,043,556	£1,011,858
Durham	£1,699,391	£1,643,431	£1,591,532	£1,543,189

Ealing	£595,497	£575,887	£557,701	£540,761
East Riding	£971,832	£939,830	£910,151	£882,505
East Sussex	£1,052,855	£1,018,185	£986,031	£956,080
Enfield	£799,117	£772,802	£748,397	£725,664
Essex	£5,604,533	£5,419,980	£5,248,817	£5,089,384
Gateshead	£427,121	£413,056	£400,012	£387,862
Gloucestershire	£977,027	£944,855	£915,016	£887,222
Greenwich	£1,191,830	£1,152,584	£1,116,185	£1,082,281
Hackney	£780,854	£755,141	£731,294	£709,081
Halton	£722,640	£698,844	£676,774	£656,217
Hammersmith	£849,952	£821,964	£796,006	£771,827
Hampshire	£4,494,996	£4,346,979	£4,209,702	£4,081,832
Haringey	£749,468	£724,788	£701,899	£680,579
Harrow	£325,087	£314,382	£304,454	£295,206
Hartlepool	£641,457	£620,335	£600,744	£582,497
Havering	£644,777	£623,545	£603,853	£585,511
Herefordshire	£1,296,818	£1,254,115	£1,214,510	£1,177,619
Hertfordshire	£2,140,629	£2,070,140	£2,004,765	£1,943,870
Hillingdon	£542,807	£524,933	£508,355	£492,914
Hounslow	£541,324	£523,498	£506,966	£491,567
Isle of Wight	£164,081	£158,678	£153,667	£148,999
Islington	£1,301,804	£1,258,936	£1,219,179	£1,182,146
Kensington	£504,235	£487,631	£472,232	£457,888
Kent	£2,114,113	£2,044,497	£1,979,932	£1,919,791
Kingston upon Hull	£307,845	£297,708	£288,307	£279,549
Kingston upon Thames	£177,777	£171,923	£166,494	£161,436
Kirklees	£890,948	£861,609	£834,400	£809,055
Knowsley	£1,040,646	£1,006,378	£974,597	£944,994
Lambeth	£679,824	£657,437	£636,676	£617,337
Lancashire	£6,074,689	£5,874,654	£5,689,133	£5,516,325
Leeds	£655,753	£634,159	£614,133	£595,478
Leicester City	£921,187	£890,853	£862,720	£836,515
Leicestershire	£1,279,615	£1,237,479	£1,198,399	£1,161,998
Lewisham	£635,813	£614,876	£595,458	£577,371
Lincolnshire	£1,755,413	£1,697,609	£1,643,998	£1,594,061
Liverpool	£4,748,077	£4,591,726	£4,446,720	£4,311,650
Luton	£452,184	£437,294	£423,484	£410,621
Manchester	£2,184,599	£2,112,662	£2,045,944	£1,983,798
Medway Towns	£793,412	£767,286	£743,055	£720,484
Merton	£331,038	£320,137	£310,027	£300,610
Middlesbrough	£2,012,543	£1,946,272	£1,884,809	£1,827,557
Milton Keynes	£728,691	£704,695	£682,441	£661,712

Newcastle upon Tyne	£1,233,153	£1,192,546	£1,154,885	£1,119,806
Newham	£644,369	£623,150	£603,471	£585,141
Norfolk	£1,518,286	£1,468,290	£1,421,921	£1,378,730
North East Lincolnshire	£189,352	£183,117	£177,334	£171,948
North Lincoln	£598,533	£578,823	£560,544	£543,518
North Somerset	£379,161	£366,676	£355,096	£344,310
North Tyneside	£673,993	£651,799	£631,216	£612,042
North Yorkshire	£1,505,686	£1,456,105	£1,410,121	£1,367,289
Northamptonshire	£857,201	£828,974	£802,795	£778,410
Northumberland	£925,688	£895,206	£866,936	£840,602
Nottingham City	£773,177	£747,717	£724,104	£702,109
Nottinghamshire	£2,918,203	£2,822,109	£2,732,987	£2,649,972
Oldham	£2,841,343	£2,747,779	£2,661,005	£2,580,176
Oxfordshire	£3,803,136	£3,677,901	£3,561,754	£3,453,565
Peterborough	£128,716	£124,478	£120,547	£116,885
Plymouth	£641,067	£619,957	£600,379	£582,142
Poole	£587,403	£568,060	£550,121	£533,411
Portsmouth	£491,763	£475,569	£460,551	£446,562
Reading	£258,732	£250,212	£242,311	£234,950
Redbridge	£816,883	£789,984	£765,036	£741,798
Redcar and Cleveland	£374,697	£362,358	£350,915	£340,256
Richmond upon Thames	£423,023	£409,093	£396,174	£384,140
Rochdale	£543,979	£526,066	£509,453	£493,978
Rotherham	£1,587,564	£1,535,287	£1,486,802	£1,441,640
Rutland	£67,888	£65,653	£63,580	£61,648
Salford	£865,145	£836,656	£810,235	£785,624
Sandwell	£1,129,191	£1,092,007	£1,057,522	£1,025,399
Sefton	£2,319,808	£2,243,419	£2,172,572	£2,106,579
Sheffield	£2,779,575	£2,688,046	£2,603,157	£2,524,086
Shropshire	£1,664,983	£1,610,156	£1,559,307	£1,511,943
Slough	£343,382	£332,075	£321,588	£311,820
Solihull	£846,645	£818,766	£792,909	£768,824
Somerset	£1,313,553	£1,270,299	£1,230,183	£1,192,816
South Gloucestershire	£914,599	£884,482	£856,550	£830,532
South Tyneside	£306,215	£296,132	£286,780	£278,069
Southampton	£441,989	£427,434	£413,936	£401,363
Southend-on-Sea	£418,867	£405,074	£392,281	£380,366
Southwark	£197,361	£190,862	£184,835	£179,220
St Helens	£1,191,321	£1,152,092	£1,115,709	£1,081,819
Staffordshire	£2,557,129	£2,472,925	£2,394,830	£2,322,087



Stockport	£1,015,373	£981,938	£950,928	£922,044
Stockton	£551,965	£533,789	£516,932	£501,230
Stoke-on-Trent	£657,547	£635,895	£615,813	£597,108
Suffolk CC	£2,558,986	£2,474,720	£2,396,569	£2,323,773
Sunderland	£896,972	£867,435	£840,041	£814,525
Surrey	£1,738,108	£1,680,873	£1,627,792	£1,578,347
Sutton	£123,742	£119,668	£115,889	£112,368
Swindon	£421,273	£407,401	£394,535	£382,551
Tameside	£799,561	£773,232	£748,814	£726,068
Telford	£924,509	£894,065	£865,831	£839,531
Thurrock	£320,565	£310,009	£300,219	£291,100
Torbay	£472,331	£456,778	£442,353	£428,916
Tower Hamlets	£422,800	£408,878	£395,965	£383,938
Trafford	£397,900	£384,798	£372,646	£361,327
Wakefield	£926,900	£896,378	£868,070	£841,703
Walsall	£890,225	£860,911	£833,723	£808,399
Waltham Forest	£1,210,036	£1,170,191	£1,133,236	£1,098,814
Wandsworth	£279,651	£270,442	£261,902	£253,947
Warrington	£580,291	£561,183	£543,461	£526,953
Warwickshire	£1,929,059	£1,865,536	£1,806,623	£1,751,747
West Berkshire	£444,463	£429,827	£416,253	£403,609
West Sussex	£4,745,060	£4,588,809	£4,443,895	£4,308,911
Westminster	£326,752	£315,993	£306,014	£296,718
Wigan	£1,603,583	£1,550,778	£1,501,805	£1,456,187
Wiltshire	£1,190,530	£1,151,327	£1,114,968	£1,081,101
Windsor	£124,076	£119,990	£116,201	£112,671
Wirral	£1,677,574	£1,622,333	£1,571,100	£1,523,377
Wokingham	£291,790	£282,182	£273,270	£264,970
Wolverhampton	£1,044,812	£1,010,407	£978,499	£948,777
Worcestershire	£3,115,042	£3,012,466	£2,917,332	£2,828,718
<b>Total</b>	<b>£176,856,300</b>	<b>£171,032,551</b>	<b>£165,631,360</b>	<b>£160,600,281</b>

## Appendix C: Freedom Of Information (FOI) Request

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Dear ,

I would be grateful for the following information:

1. How many former Independent Living Fund (ILF) recipients reside in your London Borough?
2. How many former ILF recipients who have had community care assessments have had reductions in levels of their care package funding and/or support compared to the total they received from both the ILF and the Local Authority combined before closure?

Of these how many have had reductions:

- Of under 10%?
  - Of between 10 and 20%?
  - Of between 21 and 40%?
  - Of between 41 and 50%?
  - Of over 50%?
3. The government has committed to four years' worth of funding through the former ILF Recipient Grant. Will your London borough be:
    - Ring-fencing this to care and support for former ILF recipients?
    - Ring-fencing to adult social care?
    - Not ring-fencing?
  4. How many former ILF recipients have as part of their re-assessment been referred for a Continuing Healthcare Assessment, and of these how many were found eligible?
  5. How many complaints have been received from former ILF recipients concerning their re-assessments and the outcomes thereof?
  6. How many former ILF recipients have been moved into residential care following the closure of the ILF?

## Appendix D: FOI Response Spreadsheet

Borough	No. former ILF	No. total reductions	Percentage reductions	No. under 10%
Barking/Dagenham	36	1	3%	1
Barnet	89	26	29%	8
Bexley	33	See note 1	N/A	N/A
Brent	63	7	11%	1
Bromley	42	8	19%	0
Camden	50	4	8%	2
City of London	1	0	0%	0
Croydon	65	2	3%	2
Ealing	42	1	2%	1
Enfield	Did not answer	0	0%	0
Greenwich	56	6	11%	0
Hackney	54	5	9%	1
HF	48	0	0%	0
Haringey	48	1	2%	1
Harrow	26	1	4%	0
Havering	39	20	51%	16
Hillingdon	34	4	12%	0
Hounslow	44	26	59%	7
Islington	78	0	0%	N/A
Kensington & Chelsea	30	Info not held	Not held	Not held
Kingston-upon-Thames	10	0	0%	0
Lambeth	38	2	5%	0
Lewisham	22	8	36%	Not held
Merton	19	8	42%	6
Newham	43	24	56%	8
Redbridge	50	2	4%	0
Richmond	25	4	16%	4
Southwark	15	0	0%	0
Sutton	7	0	0%	0
Tower Hamlets	27	0	0%	0
Waltham Forest	60	41	68%	0
Wandsworth	15	0	0%	0
Westminster	21	0		0
	1176			

Borough	No. 10 - 20%	No. 21- 40%	No. 41 - 50%	No. 50% +	Ring-fence
Barking/Dagenham					None
Barnet	9	6	1	2	ASC
Bexley	N/A	N/A	N/A	1	ASC
Brent	2	3	1	0	None
Bromley	8	0	0	0	None
Camden	1	1	0	0	ASC
City of London	0	0	0	0	ASC
Croydon	0	0	0	0	ASC
Ealing	0	0	0	0	ASC
Enfield	0	0	0	0	ILF
Greenwich	2	0	0	4	ASC
Hackney	0	1	0	3	ILF
HF	0	0	0	0	ILF
Haringey	0	0	0	0	ASC
Harrow	0	0	1	0	ILF
Havering	1	2	1	0	ASC
Hillingdon	1	1	1	1	ASC
Hounslow	7	7	3	2	None
Islington	N/A	N/A	N/A	N/A	ILF
Kensington & Chelsea	Not held	Not held	Not held	Not held	Not answered
Kingston-upon-Thames	0	0	0	0	ILF
Lambeth	0	0	0	2	ASC
Lewisham	Not held	Not held	Not held	Not held	ASC
Merton	2	0	0	0	ASC
Newham	4	6	4	2	ASC
Redbridge	0	2	0	0	ASC
Richmond	0	0	0	0	ASC
Southwark	0	0	0	0	Not held
Sutton	0	0	0	0	
Tower Hamlets	0	0	0	0	ASC
Waltham Forest	7	11	7	16	None
Wandsworth	0	0	0	0	ILF
Westminster	0	0	0	0	ASC

Borough	Total CHC referrals	No. CHC eligible	Complaints	Residential care
Barking/Dagenham	0	N/A	1	0
Barnet	Less than 5	Less than 5	Less than 5	Less than 5
Bexley	3	1 + 1 50/50	0	0
Brent	12	3	0	2
Bromley	0	N/A	0	0
Camden	3	3	2	0
City of London	0	0	0	0
Croydon	Not specified	3	0	0
Ealing	4	2	0	0
Enfield	Not answered	Not answered	Not answered	Not answered
Greenwich	3	2	3	0
Hackney	21	20	1	0
HF	0	N/A	0	0
Haringey	0	0	2	0
Harrow	2	2	0	1
Havering	4	4	5	0
Hillingdon	7	3	2	0
Hounslow	7	2	2	0
Islington	0	0	0	0
Kensington & Chelsea	0	0	1	0
Kingston-upon-Thames	0	0	0	0
Lambeth	1	1	0	0
Lewisham	11	11	1	0
Merton	3	2	0	2
Newham	19	2	2	0
Redbridge	3	2	1	0
Richmond	4	4	0	0
Southwark	4	Not held	0	0
Sutton	0	1	1	1
Tower Hamlets	0	0	0	0
Waltham Forest	No info available	0	19	0
Wandsworth	3	Awaiting outcome	0	0
Westminster	0	1	0	0
	93	48		

# Appendix E: London Deaf and Disabled People's Organisations' Survey

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**Name of person completing this survey (optional):**

**Deaf and Disabled People's Organisation you represent:**

(Please note that none of the responses you give to the following questions will be attributed to your organisation)

**London Borough where you operate:**

Please tick if you do not want us to include in the report any information that identifies your London borough

1) How well has the transition from the ILF to mainstream care and support been managed by your Local Authority?

- Positively
- No impact either way
- Negatively
- Don't know

What have they done well and what could they have done better?

2) The government has just confirmed four years' of funding for Local Authorities through the Former ILF Recipient grant for the next. However, this grant will not be ring-fenced. What commitment has your Local Authority made about how it will use this grant?

- Ring-fence to former ILF recipients
- Ring-fence to Adult Social Care
- No ring-fence
- Don't know

3) In your experience how has the closure of the ILF impacted on former ILF recipients in the Local Authority/ies where you operate?

- Positively
- No impact either way
- Negatively
- Don't know

In what way have they been impacted and how do you know this? Please provide any case studies and examples that you can.

4) In your experience how has the closure of the ILF resulted in more funding being available for other social care users in your area?

- Positively
- No impact either way
- Negatively
- Don't know

How do you know this?

5) How has the closure of the ILF impacted on your organisation?

- Positively
- No impact either way
- Negatively
- Don't know

If your organisation has experienced an impact, please describe what this has been.

- 6) Is there anything else you want to tell us about the impact of the closure of the ILF?

Please attach any **case studies** or **additional information** including any communications from your local authority or responses to FOI requests detailing the impact of the closure in your area, for example percentages of former ILF recipients who have experienced cuts to their social care packages.

Many thanks for taking the time to complete this survey and for any additional information you are able to send us.

The final published report will be sent to all Inclusion London members.



# Appendix F: London DDPO Survey Response Spreadsheet

Organisation	Transition management by LA	Ring-fence	Impact on recipients	Other social care users	Impact on DDPO	Notes
DDPO1	Negative	None	Negative	Negative	Negative	Underspend in social care budget
DDPO2	Positive	ILF	None	Don't know	Negative	Extra work
DDPO3	Negative	Don't know	Negative	Negative	Negative	Increase in enquiries
DDPO4	Negative	ILF	Negative	Negative	No impact	
DDPO5	No impact	ILF	None	No impact	No impact	Underspend in social care budget
DDPO6	Negative	Don't know	Negative	Don't know	Negative	Extra work with limited resources
DDPO7	Negative	None	Negative	Negative	Negative	Extra workload/draining for staff
DDPO8	Negative	Don't know	Negative	Don't know	Negative	
DDPO9	Positive	Don't know	None	Don't know	No impact	
DDPO10	Negative	Don't know	None	Don't know	No impact	
DDPO11	Negative	ASC	Negative	No impact	Negative	Director of DDPO lost support
DDPO12	N/A	N/A	Negative	Don't know	Negative	Members do not want to engage, not know what will happen with their support
DDPO 13	N/A	N/A	Negative	No impact	Negative	Huge amounts of extra work for no extra funding
DDPO 14	N/A	N/A	Negative	Negative	Negative	

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