

“Imposed unknowns”: a qualitative study into the impact of ILF closure on users

Abstract

The Independent Living Fund (ILF) was a non-departmental public body funded by the Department for Work and Pensions. An efficient and popular system of support, the ILF enabled 46,000 people between 1988 and 2015; however, in 2015 the Fund closed and local authorities (LAs) assumed sole responsibility for supporting former ILF users. This paper presents the experiences of 12 former ILF users as they transition from ILF to LA support. We focus on participants’ experiences of ILF and LA support, their transition from ILF to LA support, and the emotional impact of transition. Participants were universally positive about their dealings with the ILF, whilst nearly all were worried about LA provision. For most participants, the process of transfer was not smooth; participants received insufficient information and poor communication from LAs. Participants expressed anxiety and uncertainty over the future and these feelings were exacerbated by the actions of LAs during transfer.

Key words: Independent Living Fund; Qualitative; Disability; Social Care; Emotion

Background

Enabling people with complex needs to control their own lives and to live in the community is central to any vision of disability equality (Ratzka 1992; UN 2006). Many Northern European countries now have personal assistance schemes (Autio and Sjöblom 2015). Independent living has been a key component of the UK disability rights movement, from the early days of the Union of Physically Impaired Against Segregation (Barnes 2005; Morris 1993, 1997), and self-operated care schemes developed in Derbyshire, Greenwich, Hampshire and other areas (Morris 1993). An obstacle to direct payments for personal assistance was the legal restriction in disbursing government funding to individuals. In UK, the Independent Living Fund (ILF) was established in 1988 to meet the support requirements of disabled people left disadvantaged by the 1886 Care Act. Because it was an independent charity, it was a mechanism for circumventing the legal restriction. Initially, the ILF was expected to support a relatively small number of disabled people (hundreds rather than thousands) and had an annual budget of just £5m. However, once

open, the ILF revealed a huge demand for independent living and self-directed support among disabled people. Uptake of the ILF quickly outpaced government predictions, and by 1992 the ILF was serving 22,000 disabled people and had an annual budget of £97m (Hudson 1994).

Following the rapid expansion of the ILF, successive governments sought to limit access and reduce costs. The ILF was closed to new applicants in 1992, with the intention that it would be fully closed in 1993. However, the government's efforts to close the Fund were met by a strong and effective lobby for its preservation. Disability rights organisations succeeded in preventing the Fund's outright closure, and in 1993 a second fund was created to support new applicants ("Independent Living 1993 Fund") and from 1993 to 2007, the two funds operated in tandem. Meanwhile, the 1996 Community Care (Direct Payments) Act made it legal for local authorities to make direct payments to disabled people for their personal assistance, and increasingly, personal assistance developed as an alternative to homecare (Shakespeare 2014). The ILF supported over 46,000 people between 1988 and 2015 (ILF 2015a); however, in December 2010 it was announced that the ILF would close permanently.

Legal challenges followed in the High Court and then the Court of Appeal, centring on whether or not the government had complied with its legal obligations under the Public Sector Equality Duty as required by the Equality Act (Gradwell 2015). In March 2014 Mike Penning, Minister of State for Disabled People, restated the government's decision to close the ILF as of the end of June 2015, and despite a final legal challenge, closure went ahead.

Why close the ILF?

As rationale for the closure of ILF, the Department for Work and Pensions cited four factors (DWP 2014, 8). First, local authorities engaged with the ILF to varying degrees, which resulted in an uneven distribution of resources. Many local authorities accessed the ILF; however, one quarter of these local authorities accounted for 55% of ILF funding. Accordingly, the DWP posited that closure would result in a more even distribution of resources across the country (DWP 2014, 8).

Second, it was argued that disabled people did not have equitable access to ILF resources. The ILF was closed to new applicants in 2010 meaning that some disabled people continued to be supported by the ILF, whilst others were not. The DWP stressed its responsibility to all disabled people, and insisted that complete closure was necessary to achieve a fairer funding system for all disabled people (DWP 2014, 8).

Third, the DWP claimed that devolving authority and resources to local authorities would result in more consistent and efficient support for disabled people. Thus, the DWP stated that 'there would be some benefits for [social care] users as the resources available to them... would be provided from a single source, making things simpler and more straightforward for the user' (DWP 2014, 8).

Finally, the DWP believed that personalisation would deliver flexible and empowering local authority services: 'the mainstream adult care and support system now includes, (or very soon will include), many of the features currently associated with the ILF such as direct payments and personal budgets' (DWP 2014, 19). The ILF, the argument claimed, was now redundant as local authorities had embraced and enacted the personalisation agenda.

Transitional arrangements

Five years passed between the announcement that the ILF would close and its eventual closure. One benefit of such a protracted endgame was that ILF users had advanced warning of the transition to local authority support. Prior to closure, ILF users, local authorities and disability organisations all stressed the need for carefully planned and well-communicated transfer arrangements. To this end, the ILF published guidance for its users about what to expect during the transition from ILF to local authority funding (ILF 2015b), guidance that was endorsed by the Association for Directors of Adult Social Care (ADASS 2014).

From the ILF perspective, each user was involved in a six stage 'transfer review programme'. Stage one involved initial contact between ILF assessors and local authorities; a transfer review visit was arranged (a representative from the local authority was invited to attend). Next, ILF users received a letter detailing their transfer review visit and a financial information form, which they were required to complete and return. Stage three saw the

transfer review visit; ILF users would be asked about their independent living outcomes, the support they needed, and the resources available to them. At stage four the ILF compiled an ILF support plan, which was disseminated to both the user and the local authority (this support plan was intended to inform local authorities as to the future support of users), and the ILF user received an offer of ILF support. Finally, stage six involved the ILF making payments until the date of ILF closure.

Impact of closure

Prior to closure, relatively little was known about how local authorities planned to support former ILF users after June 2015. One concern was that the funds transferred from central government to local authorities would not be ring fenced for former ILF recipients, or even for adult social care. A freedom of information request submitted by Disability Rights UK (April 2015) revealed that as few as 9 local authorities planned to ring fence ILF monies for former recipients. A further 22 local authorities reported that no decision had been taken by January 2015 (DRUK 2015).

In June 2015 the only official gauge as to the impact of closure were the DWP's public consultation and equality impact assessment. The DWP's impact assessment found that ILF users were likely face reductions or alterations to their care package (DWP 2012a), with people with learning disabilities being disproportionately disadvantaged; people with learning disabilities accounted for 36% of ILF recipients, compared with just 15% of higher-rate DLA recipients (DWP 2014, 10). Despite recognising these issues, the DWP impact assessment stated that it was not possible to quantify the impact of ILF closure.

Another indicator as to the impact of closure was the DWP's public consultation, which canvassed opinion from ILF users, disabled people's organisations, and local authorities. Respondents were asked about their views on the closure of the ILF and the transition to local authority funding. Various concerns were highlighted (DWP 2012b):

- ILF users feared they would be unable to live independently without ILF support. Whilst some local authorities were committed to matching the levels of support provided under the ILF, this was the exception rather than the rule. Where local

authorities did not match the levels of funding provided under the ILF, former ILF users feared they would be forced to resort to institutional care rather than community living.

- ILF users were concerned about the principles that underpin local authority assessments. Some said that local authority assessments were less person-centred (than the ILF) and guided by budgetary constraints rather than independent living principles.
- ILF users worried that local authority services would permit fewer choices and less control. Specifically, ILF users said that local authority restrictions over the use of direct payments was likely to result in more rigid support arrangements, with limited possibilities for social participation and fewer opportunities for education and employment.

Anecdotal evidence suggested that former ILF users had encountered difficulties during the transition to local authority support (Pring 2015). However, there remains a lack of data that show how users experienced closure and transition; this paper addresses this issue.

Study design and methodology

The data presented in this paper are taken from 12 in-depth interviews conducted as part of an ongoing ESRC study into personal assistance relationships. Participants were sampled opportunistically from the larger study: the primary (ESRC) study sampled purposively (the criteria of which involved the use of personal assistants) with participants for the current paper selected on the basis that they were ILF users.

Recruitment occurred through three centres for independent living (CIL) across six local authorities. When participants made contact with their respective CILs, CIL representatives asked whether they were happy to receive information and invitation to the current study. Participants then made contact with the study team, at which point further information about the study was provided. Participants provided informed consent by post; informed consent was reaffirmed at the beginning of each interview.

The study sample consisted of seven women and five men aged between 27 and 64, all of who have a physical impairment. A range of ethnic backgrounds were sampled – seven white British, one white Irish, one black British, and three British Asian participants.

Interviews took place between February and June 2015 and were structured by a topic guide, which included questions about participants' experiences of ILF support, their transfer to local authority support, and their feelings about future support provided by their local authority. The topic guide was flexible and participants were able to shape the course of interviews whilst the content remained pertinent to the ILF and their transition to local authority funding (Arthur and Nazroo 2003).

The majority of interviews were conducted in participants' own homes, although four were conducted by telephone. Interviews were transcribed by the interviewer (TP), following which all data management and analysis were conducted jointly within the research team (TP and TS) using QSR Nvivo 10. Transcripts were subject to thematic analysis (Braun and Clarke 2006) underpinned by a critical realist ontology and epistemology (Danermark and Gellerstedt 2004; Williams 2001).

Ethical complications in this study were negligible, however several participants became upset when discussing the process of transfer and their prospects of independent living following the Fund's closure. When participants became distressed, interviews were temporarily suspended, and time was taken to ensure each participant's wellbeing and to establish whether or not they wished to continue. Further, where participants became distressed, the interviewer made contact (by telephone) several days later to ensure their wellbeing.

Findings

Strengths of the ILF

All participants had used the ILF for longer than five years and all regarded the ILF positively. Participants identified the ILF's philosophy of independent living and its flexible working practices as key to their having flourished under the Fund's support.

Ian, a 45 year old white Irish man with a musculoskeletal condition, highlighted the ILF's philosophy of independent living, saying that the ILF was 'all about control and choice'. An artist and musician, Ian detailed how the ILF had helped him to take risks and pursue opportunities in a safe and supported way. In Ian's words, the ILF meant:

Being able to negotiate with someone to say "I am doing this, I don't know where it's going to lead me but it's certainly where I am going and I need help to do it, just hold my hand, I am still going to need you to do my physical care for me, but it might be in a strange place".

Sarah, a 46 year old white British woman with physical impairment, regarded the ILF's approach in a similar way. Sarah said that the ILF held an holistic understanding of independent living, which meant much more than just 'washing, dressing, cleaning teeth, food preparation'. Like Ian, Sarah's experiences of the ILF had been empowering; she explained that unlike her local authority, the ILF understood her personal circumstances, recognised and valued her aspirations, and supported her to 'be an individual'.

Participants also gave concrete examples of the ILF's flexible working practices, which enabled them to access support with minimal stress, and which built trust in the ILF as an organisation intent on supporting its users. Angela, a 58 year old White British woman with spinal cord injury, contrasted the working practices of the ILF with those of her local authority and said that the ILF were 'much more approachable, they are easier to ask questions of'. Angela said that queries to her local authority often went unanswered, whilst in contrast, the ILF 'seem to have their fingers on the pulse because that's all they do'. For Paula, a 62 year old white British woman with multiple sclerosis, having a single point of contact within the ILF had been beneficial: 'you always have a point of contact, and my email was direct to him'. This continuity meant that for Paula, communication with the ILF was straight forward, 'you rang up, they'd have someone on the switchboard... you say what your surname was and they put you through to your case worker'. Paula said that the ILF's procedures of assessment and audit were 'easy' in comparison to those of her local authority:

The ILF do it once a year when they come out to you to assess you, all your paperwork is – it's not that much – is there. They look through it all, check it all, then they do their assessment. Not an issue, it's easy paperwork.

Limitations of local authorities

In contrast to participants' positive experiences of ILF support, all but one participant described their dealings with their local authority negatively. The wider context was that local authorities were facing tight funding constraints and cut backs (ADASS 2015).

However, many participants contrasted the 'light touch' approach of the ILF with the 'rigid' approach experienced with local authorities, which many felt was bureaucratic, confusing, and onerous.

Liz, a 46 year old white British woman with physical impairment, found her local authority's systems to be inefficient. She described the 'complete inconsistency' she had experienced within her local authority: 'you get a different social worker each time', adding that 'they don't always read the notes and you have to go through the whole assessment thing over and over again, it's all needs based and very bureaucratic'. Liz also worried about her local authority social workers' ability to manage her support:

They're nice enough, but not very professional... I have to tell them what forms to fill out – it's been that bad. They don't always read the notes and you have to go through the whole assessment thing over and over again.

Similar issues were highlighted by Paula, who said that her dealings with her local authority were impersonal, anonymous, and had 'no continuity going on whatsoever'. Paula, who lives alone in an isolated rural area without any family network, found communication with her local authority to be 'very confusing'; Paula said that 'you never speak on the phone to the same person twice', adding that 'you couldn't get them directly, you had to go through customer services and they put you through so it was never a personal thing'. These experiences left Paula feeling 'like another blooming nuisance'.

Jessica, a 27 year old white British woman with a spinal cord injury, said that she had been forced to keep a diary of her needs in order to justify local authority support. Jessica, who was a long-term user of both local authority and ILF support, worried about an upcoming

local authority assessment to determine her future funding post-ILF. Specifically, Jessica's abiding hope was to return to work, yet her experience of local authority support left her pessimistic about this prospect: 'the ILF seem to take a lot more time understanding your needs, what you're wanting to do, what they're supporting you with, whereas social services doesn't appear to be like that'.

Transfer review programme

The transfer review programme was the cornerstone of ILF and local authority plans to deliver carefully planned and well-communicated transfers (ADASS 2014: ILF 2015b). At the time of interviews, all participants had undergone a transfer review meeting with a representative of the ILF. However, contrary to best practice, not all of these meetings were attended by a local authority representative. Unfortunately, participants' accounts of these meetings and subsequent communication with local authorities, suggest that often, transfers were neither carefully planned nor well-communicated.

Angela was one of the few participants who received a joint ILF and local authority assessment. Despite this, Angela remained confused about the purpose of this meeting and the role of the local authority representative. Speaking about the local authority representative, she said:

I think she was from the council, but there's so many different arms involved [in transfer] that you're never sure who's visiting you, whether she's council, whether she's from the social work side of it, the monetary side of it, or whatever... I don't know.

One participant, Ian, said that he was happy with his transfer review meeting:

I went through my care plan and my needs and stuff and I was sort of happy with what I had – a few little changes here and there, but essentially it was just the review led to, I was okay as I was.

However, Ian also questioned the short period of time in which his local authority had been involved in his transfer, and whether he would be supported in a similar way once his local authority took sole control over his funding:

It's only since January that we have had any sort of dialogue and that's one meeting and a letter... that doesn't build confidence in me to say that a system that has worked for me for twenty years is going to be alright in July [after ILF closure].

In contradiction of ADASS recommendations (ADASS 2015), only one participant's local authority, Liz, had involved ILF users in managing the transfer. However, Liz's experience of her local ILF user group had not been positive. Liz explained that her local authority had been 'really shoddy about getting notice out to people about meetings, the minutes never follow through, there has been a different local authority rep at each group. Communication is pretty bad'. Liz also said that her local authority projected an unrealistic sense of control over transfer, which contributed to her feelings of uncertainty over the future: 'they try and make out that they're on the ball and they know what they're doing, but they don't. To a certain extent they can't because no one knows'.

ILF users' fears

Given the patchy implementation of the transfer review programme, and participants existing concerns over local authority support, it is unsurprising that many harboured fears about the future.

Jessica, who was supported to live independently in her own home, but whose local authority had not ring fenced ILF funds, was concerned that her local authority would not spend the ILF monies transferred from central government on independent living: 'that scares me... I think it's just going to be too easy for them [local authority] to give money to other things'. Uppermost in Jessica's mind was the fear that her local authority would reduce the hours of personal assistance it funded, a move which would leave her unable to live independently: 'they will cut it down to one person and that doesn't work. It doesn't work in real life, it works on paper, that's what worries me about the council.' Jessica added that any cut in her levels of support would damage her health, leaving her unable to participate in community life: '[It] would effectively end up with me being bedbound and as I've already got pressure sores it's not a good idea. And I know my quality of life would drop insanely if my care dropped less'.

Similar issues were raised by Angela, who said that her local authority applied more stringent assessment criteria than the ILF and sought to reduce her use of social services: 'They've been saying, "where can I save money?", they say "what are you using carers for?", "that isn't applicable", like what can I get from voluntary services, voluntary agencies or whatever'. Angela had unanswered questions over her future funding package, and how this would affect her life:

Is it going to work? Are they going to pay on time? And what sort of... is the money going to stay the same? Are they going to reduce the budget once they realise what they've taken on.

Emma said that her greatest fear was losing her independence and the prospect of institutional care: 'at no point, please, I cannot have mentioned in my vicinity the words "care home"'. Speaking about the prospect of losing her independence, Emma said 'it's just not an option for me... it *will* never happen'. Emma concluded by saying 'I've got Morphine and I know what I can do with it, so don't bother even suggesting that, not going to happen'.

Communication

Most participants were desperate for information about the transition and whether or not their funding package would change under local authority provision. However, all but one participant said that the information provided by their local authority had been inconsistent and insufficient, and that a lack of communication had exacerbated their concerns. Sarah was exemplary in this sense: 'I feel I haven't been communicated with. I haven't, I still don't really know what's happening. I think I know what might happen but I haven't actually got anything saying that'.

Sarah's situation was typical in that whilst she knew that she knew her local authority were to receive ILF monies from central government, she had not been told how this would affect her funding package after June 2015:

As yet I have had no actual confirmation that the ILF money that I have been receiving... although I know that the social services will receive it for a year, I haven't actually had confirmation that that is what they're actually going to do.

Hakim, a 30 year old British Asian man with cerebral palsy, said that a lack of communication from his local authority – which he termed ‘deliberate vagueness’ – left him uncertain over his future support arrangements:

Someone did ring me to say that they’re going to match what I currently have. Now, I don’t know how flexible that is. I don’t know how adaptive that’s going to be, so if I ask for more hours because I need them for some reason, will I get them?

Another participant, Jessica, said that communication with her local authority throughout the transfer had been ‘poor, very poor’. When asked about the process, Jessica said ‘all I seem to get is more forms and more forms and more forms’ and criticised the ‘call centre culture’ operated by social services, which she felt were ill-suited to the support of people with complex health profiles: ‘social services try to use a call centre to manage someone’s long-term care issues’.

Angela was also unsure about what the transfer would mean in practice. She was concerned about whether or not she would be able to use her funding in the same way as under the ILF; these concerns had not been addressed by her local authority, a situation which added to her sense of uncertainty:

Nobody has told me how it’s going to... if it’s going to change. Will it be a seamless transfer where it doesn’t change at all or is there going to be some sort of limit as to what you can do? You want answers to this before. There is nothing I can do about the change, I know, but I would like to know these things before they change, so that we can prepare for it.

Emotional impact

Participants fears over the closure of the ILF and the future of local authority provision, coupled with poor communication from local authorities, resulted in feelings of anxiety, stress and in one case, suicidal thoughts.

Ian said that his fears about the future were ‘not the fear of change’, but rather, the loss of certainty to be replaced by uncertainty: ‘they’re asking us to give something up without

really knowing what's in its place'. Ian explained that this loss of certainty once provided by the ILF, was exacerbated by his local authority's management of the transition: 'these are imposed unknowns that I am being asked to consider without any genuine dialogue, without feeling like my voice is being listened to, without feeling that I have been considered'.

Sarah, a 43 year old white British woman with physical impairment, told of the impact that uncertainty over future support arrangements had on her wellbeing:

I started dreaming about it... the dreams are so real, I dreamt they'd sent me a letter offering me a residential place costing £778 of which they were going to pay £700... that's a third of what I am getting currently... it was so realistic I was actually looking for the letter the following day... so it's obviously in my mind at the moment. Horrible.

At the time of her interview, Sarah's local authority had not provided clarification over her future funding arrangements. When asked how this made her feel, Sarah replied:

Very stressed, because I tend to suffer from stress anyway and it hasn't helped. I think possibly that my state of health is not particularly good... because at the end of the day it's stressful, I find it stressful anyway. [Participant visibly upset.] So, it's just nice to know where you stand... I haven't had any written confirmation, I have just had the social worker saying that's what she would recommend.

Paula also described the rigid assessment procedures of her local authority and explained that she was forced to think of herself as the 'worst possible, useless amount of thing you can do and that's what they focus on and tick a box'. When asked how these assessments made her feel, Paula sighed and replied 'Can I use the word "crap"? Because crap is how it makes you feel.' At this point, Paula began to cry, yet made a point of adding 'In all my dealings with social services, not at any point have I felt like a person. My own person. That gets me upset'. Several minutes later, with Paula less distressed, she expressed her sense of foreboding: 'I am not looking forward to this June thing at all, I'm going to be really screwed'.

Liz's local authority planned to maintain her IFL support until 2016; however Liz explained that this extension simply prolonged the period in which she lacked clarity over the future: 'Yet again, we're waiting for the hammer to fall. This constant waiting game. We have to wait now to see what will happen in 2016'.

Study limitations

This study has a small sample size. However, the sample includes service users from six different local authorities, and a broad range of ages and ethnic backgrounds are included. All participants in this study may be regarded as high-level users of support (approximately half received full-time support, and 10 of the sample were group 2 ILF users which means they have been assessed by their local authorities as having substantial or critical levels of need). For such users, local authorities play a significant role in shaping independent lives and quality of life.

However, the sample does not include any participants with learning difficulties; this is regrettable, as approximately one third of the users of the ILF were people with learning difficulties and this study does not capture their experiences of the ILF and their transfer to local authority support. Finally, this paper presents data from a single interview prior to June 2015 and would be strengthened by a longitudinal design which followed up participants after transition. To address this limitation, the research team intends to conduct further interviews with this cohort of participants (at three and six month intervals) to understand the impact of ILF closure over time.

Discussion and conclusions

Participants in this opportunistic study recognised and valued the principles of independent living that underpinned the ILF's working practices, which, participants said, were flexible, accommodating, and contributed to their having flourishing under the Fund's support. Despite its flaws (Watch 2015), the ILF was an extraordinarily popular and efficient system of support – at the time of closure, the Fund had a 98% user satisfaction rating and 98 pence

of every pound spent by the Fund went to users (ILF 2015c). As such, it is unsurprising that all participants in this study recalled the ILF with near universal praise

In contrast to the ILF, participants' experiences of local authority support left them fearful over future support arrangements. Participants questioned the principles that underpin local authority working practices – local authority assessments, participants said, were informed by a minimalist understanding of independent living. Participants also derided local authority systems, which they said were bureaucratic, confusing, and onerous.

The ILF's transfer review programme appears to have been ineffective in countering user's concerns; the review programme was well meaning, but lacked the means to affect users' future support arrangements. Only one participant underwent a joint ILF and local authority assessment (considered best practice), whilst others remained confused about the purpose of their reviews and uncertain about their outcomes. The most salient theme in the data was that of communication, or the lack of communication provided by local authorities during transfer. Participants were desperate for information about their future funding arrangements, and the glaring lack of such information did nothing to allay participant's fears, rather they were left with greater uncertainty about the future. All but one participant expressed feelings of anxiety, stress, and one participant made reference to suicide.

The ILF transition has occurred at the same time as policies of austerity and "welfare reform" have threatened the financial security of disabled people (Garthwaite et al. 2014). Thus, it is unsurprising that when faced with the prospect of dramatic cuts to their weekly income, participants in this study described feelings of stress and anxiety. Well-established evidence links financial insecurity to psychological well-being and stress: increases in poverty are known to result in stress and negative psychological well-being, whilst decreases in poverty have the opposite causal effect (Haushofer and Fehr 2014; Modrek, Hamad, and Cullen 2015). Participants' fears have been exacerbated by the seemingly insouciant actions of government, both central and local, towards disabled people.

Prior to the ILF's closure, the UK government argued that mainstream adult social care systems had evolved to include many of the features once associated with the ILF including direct payments and personal budgets (DWP 2014). However, it remains to be seen whether

or not these mechanisms lead to positive outcomes. Recent research suggests that self-directed support (in its current guise) may actually result in poorer services due to increases in bureaucracy and reductions in service user engagement (Slasberg et al. 2013, 2014).

The qualitative data presented in this study suggest that the culture of local authorities, themselves facing dramatic funding cuts, is often less empowering than that of the ILF, which was dedicated to promoting disabled people's choices and independence. As an organisation, the ILF genuinely embraced co-production with its users, and it was this (not simply its use of direct payments) which resulted in the greatest enhancements in services for users (ILF 2015). We argue that local authorities should learn from the ILF, and co-produce systems and working practices with users; this is likely to be the only viable way to change organisational culture.

As well as the ILF experience, lessons may be learned from how other countries arrange social care for high-level users. In Sweden, while local municipalities fund personal assistance for low level users, high level users are funded centrally (Clevnert and Johansson 2007; Westberg 2010). Service users who qualify for more than 20 hours are supported by the national Försäkringskassan (social insurance agency). This offers clear benefits for users and authorities alike. An agency with expertise in arranging the funding and support of high-level service users offers consistency at a national level. At an individual level, it enables case managers to build personal relationships with their service users, whilst at the same time being integrated within national level policies, thus making postcode lottery provision less likely. In England, where the numbers of high-level service users are small compared to total numbers of social care recipients, such an approach may be advantageous, resulting in levels of user satisfaction and efficiency lost with the closure of the ILF. We therefore echo Barnes (2005) in calling for increased user involvement at all levels of policy and practice and for the feasibility of an National Centre of Independent Living to be explored.

Any change is hard to manage, and the transition of some 22, 000 people from ILF to local authority support would be challenging in any circumstances. However, this study has shown that this transition has been unnecessarily arduous for former ILF users, and has resulted in stress, distress, and damage to some participants' mental health. Local authorities face unprecedented challenges in funding, yet participants' reports of local authorities' efforts to communicate with former ILF users and facilitate their transition paint

a lamentable picture. Arguably amongst the most vulnerable disabled people in the country, they have faced lack of information and insufficient communication, which has resulted in confusion and uncertainty. In June 2015 Ray James, President of the Association of Directors of Social Services was reported to have issued an apology to ILF users for transition difficulties, blaming the tough financial environment and the actions of central government (Pring 2015). For this apology to be meaningful, the experiences of former ILF users should be recognised, understood, and lessons learned about the administration of support by local authorities.

References

Arthur, S. and Nazroo, J. 2003. "Designing field work strategies and materials." In *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, edited by Ritchie, J. and Lewis, L. 109-137. London: Sage.

Association of Directors of Adult Social Services (ADASS). "ADASS Budget Survey 2015: Report". June 2015. Accessed 1 September 2015.

http://www.adass.org.uk/uploadedFiles/adass_content/policy_networks/resources/Key_documents/ADASS%20Budget%20Survey%202015%20Report%20FINAL.pdf

Association of Directors of Adult Social Services (ADASS). 2014. "Updated Transfer Review Programme Code of Practice". Accessed 1 June 2015.

http://www.adass.org.uk/uploadedFiles/adass_content/policy_networks/physical_and_sensory_impairment_and_HIVAIDS/key_documents/Updated%20England%20Code%20of%20practice%20-%20March%202014.pdf

Autio, A. and Sjöblom, S. 2015. "Entitled to Personal Assistance? An Overview of the Service in Six Nordic and Western Countries". Paper presented at the Nordic Network on Disability Research, Bergen, Norway, May 6-8.

Barnes, C. 2005. "Independent living, politics and policy in the United Kingdom: A social model account." *Review of Disability Studies: An International Journal* 1(4): 5-12.

Braun, V., & Clarke, V. 2006. "Using thematic analysis in psychology." *Qualitative research in psychology*, 3(2): 77-101.

Clevnert, U., & Johansson, L. 2007. "Personal assistance in Sweden." *Journal of Aging & Social Policy* 19(3), 65-80.

Danermark, B. and Gellerstedt, L. C. 2004. "Social justice: redistribution and recognition—a non-reductionist perspective on disability." *Disability & Society* 19(4): 339-353.

Department for Work and Pensions (DWP). 2012a. "Closure of the Independent Living Fund (ILF) and integration into mainstream care and support system: Equality Impact Assessment". Accessed 1 June 2015.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/220297/closure-of-independent-living-fund-eia.pdf

Department for Work and Pensions (DWP). 2012b. "Government response: Consultation on the future of the Independent Living Fund". London: HMSO.

Department for Work and Pensions (DWP). 2014. "Closure of the Independent Living Fund (ILF)". Accessed 5 June 2015.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/287236/closure-of-ilf-equality-analysis.pdf

Disability Rights UK (DRUK). 2015. "Most councils will not ring fence ILF resources". April 8. Accessed 1 May 2015. <http://www.disabilityrightsuk.org/news/2015/april/most-councils-will-not-ring-fence-ilf-resources>

Garthwaite, K, Bamba, C, Warren, J, Kasim, A & Greig, G. 2014. "Shifting the goalposts: a longitudinal mixed-methods study of the health of long-term incapacity benefit recipients

during a period of substantial change to the UK social security system.” *Journal of Social Policy* 43(02): 311-330.

Garthwaite, K. 2014. “Fear of the Brown Envelope: Exploring Welfare Reform with Long-Term Sickness Benefits Recipients.” *Social Policy & Administration* 48(7): 782-798.

Gradwell, L. 2015. “Independent Living Fund—from the sublime to the ridiculous?” *Disability & Society* 30(9): 1428-1433.

Haushofer, J., & Fehr, E. 2014. “On the psychology of poverty.” *Science* 344(6186): 862-867.

Hudson, B. 1994. “Independent living for disabled people in Britain: too successful by half? The case of the Independent Living Fund.” *Critical Social Policy* 14(14): 99-96.

Independent Living Fund (ILF), (2015c). “Independent Living Fund (2006) Annual Report and Accounts 2014-15”. Accessed 1 June 2015.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/435825/ilf-annual-report-2014-2015.pdf

Independent Living Fund (ILF). 2015b. “Your transfer guide”. Accessed 1 July 2015.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/439711/ilf-your-transfer-guide-england.pdf

Independent Living Fund (ILF). 2015a. “Twenty-seven: 27 years of providing independent living support”. Accessed 1 June 2015.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/432380/twenty-seven-independent-living-fund-report.pdf

Modrek, S., Hamad, R., & Cullen, M. R. 2015. “Psychological well-being during the great recession: changes in mental health care utilization in an occupational cohort”. *American Journal of Public Health* 105(2): 304-310.

Morris, J. 1997. "Care of empowerment? A disability rights perspective." *Social Policy & Administration* 31(1): 54-60.

Morris, J. 1993. *Independent Lives: community care and disabled people*. London: Macmillan.

Pring, J. 2015. Councils apologise over ILF delays and confusion, but blame government. *Disability News Service*, June 19. Accessed 1 July 2015.

<http://www.disabilitynewsservice.com/councils-apologise-over-ilf-delays-and-confusion-but-blame-government/>

Ratzka, A. 1992. "What is your personal definition of Independent Living?" Accessed 1 August 2015. <http://www.independentliving.org/toolsforpower/tools11.html>

Slasberg, C., Beresford, P., Schofield, P., & Harlow, E. 2013. "The increasing evidence of how self-directed support is failing to deliver personal budgets and personalisation." *Research into Policy and Planning*, 30: 91-105.

Slasberg, C., Watson, N., Beresford, P., & Schofield, P. 2014. "Personalization of health care in England: have the wrong lessons been drawn from the personal health budget pilots?." *Journal of Health Services Research & Policy*. 19(3): 183-188.

Shakespeare, T. 2014. *Disability Rights and Wrongs Revisited*. Oxford: Routledge.

United Nations (UN). 2006. "Convention on the Rights of Persons with Disabilities".

Watch, L. (2015). "In celebration of the closure of the Independent Living Fund." *Disability & Society*, 30(9), 1434-1438.

Westberg, K. (2010). "Personal Assistance in Sweden". Accessed 1 August 2015.

<http://www.independentliving.org/files/Personal Assistance in Sweden KW 2010.pdf>

Williams, S. J. 1999. "Is anybody there? Critical realism, chronic illness and the disability debate." *Sociology of Health & Illness* 21(6): 797-819.