



Disabled People Against Cuts

Independent Living Fund Closure Factfile

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Disabled People Against Cuts:

DPAC is a grass roots campaign body. It was formed by a group of disabled people after the first mass protest against the austerity cuts and their impact on disabled people held on the 3rd October in Birmingham 2010, England. It was led by disabled people under the name of The Disabled Peoples' Protest. DPAC has over 15,000 members and supporters and works with many anti-cuts groups, Universities, Disabled Peoples' Organizations, and Unions

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Table of Contents

Summary Grid of ILF changes: chronology.....	4
Summary	6
Independent Living in UK.....	1
Background to the Independent Living Fund (ILF).....	1
Institutionalisation arising from changes to ILF in 2010.....	3
Legal/administrative changes.....	4
Impact of Changes on disabled People.....	4
Other events/ circumstances involved in the situation.....	5
Draft Social Care Bill	5
Local Authority Care in Crisis.....	5
These are testimonies from around the UK of how disabled people will be affected by the closure of the ILF.....	7
Why the ILF court case is likely to show chances for reversing the government decision on the closure of ILF are nonexistent.....	10
Grave and Systematic Violations.....	11
ILF Closure and further Impacts on Independent Living.....	12
ILF and Independent Living: actions by UK Government as a breach of the UNCRPD in the UK .	13

Abbreviations Used

ILF – Independent Living Fund LA – Local Authorities

Equality and Human Rights Commission -EHRC Joint Committee on Human Rights-JCHR

DWP – Department for Works and Pensions MP – Member of Parliament

Summary Grid of ILF changes: chronology

<u>Year</u>	<u>Description: The Independent Living Fund (ILF)</u> Structure of ILF: The Independent Living Fund (ILF) is an Executive Non-Departmental Public Body of the Department for Work and Pensions. The Department for Works and Pensions is a Westminster Government department covering the UK. ILF is managed by a Trust (ILF Trust) but allocation of funding comes from central Government. All decisions on funding allocations for ILF come from central Government via the Secretary of State.	<u>Notes</u>
1988	Independent Living Fund (ILF) established to support disabled people with complex needs to live independently in the community by providing cash awards From Government description: "This support enables disabled people to choose to live in their communities rather than in residential care" and is "...to support the cost of their personal assistance, enabling them to live fully inclusive independent lives in their communities".	
1993	new rules come in for new users who must qualify for local authority funds to get ILF: this was effectively a cap on ILF provision because new individuals applying to ILF now needed to be receiving a sum of £320 a week from local authorities to apply for ILF. As such they must undergo two assessment phases. The original fund was wound up, but existing applicants still supported. From 2007 ILF was renamed ILF (2006). Henwood and Hudson review of ILF commissioned June 2006, published Jan 2007 recommendations include that ILF should be under local authority control by 2012	<i>no formal consultation process, no monitoring of equality impacts, no data process put in place to measure impacts or drop in numbers receiving ILF support or any increased institutionalisation of disabled people by local authorities or central government</i> <i>-1992 figures on ILF were 22,000 across the UK other numbers affected cannot be obtained as no monitoring or definitive data collection was attempted</i>
2010 March 12 th	Limiting change in qualifying rules for ILF new applicants must be working 16 hours a week , criteria apply from May 1st 2010 Trustees of ILF notified local authorities that ILF could only accept new applicants who were working 16 hours a week from May 1 st . In March and April ILF received 2600 applications, an increase of 435% on the levels ILF would	<i>no formal consultation process, no monitoring of equality impacts, no data process put in place to measure impacts or drop in numbers receiving ILF support or any increased</i>

	normally expect and 60% of what they would expect to receive in a year. A Government Equality Impact document suggested only that local authorities would monitor any adverse affects to our knowledge this has not been done.	<i>institutionalisation of disabled people by local authorities or central government</i>
2010 May 13th	Additional funding refused by the Government Trustees formally approached the Department for Works and Pensions for additional monies for applications received in March and April. This was refused.	<i>no formal consultation process, no monitoring of equality impacts, no data process put in place to measure impacts or drop in numbers receiving ILF support or any increased institutionalisation of disabled people by local authorities or central government</i>
2010 June 17th	Temporary closure to new applicants for financial year 2010/April 2011 Trustees forced into position where no new offers of ILF funding could not be made as additional funds were not provided from the Department for Works and Pensions, clause 8 of the Trust Deed specified that trustees must manage funding within available resource allocations <i>Funds were not paid if an individual application had been received but funds had not yet been allocated by the Trust to that individual.</i>	<i>no formal consultation process, no monitoring of equality impacts, no data process put in place to measure impacts on drop in numbers receiving ILF support or any increased institutionalisation of disabled people by local authorities or central government-no apparent data on instances where applications were made, but funds were not paid</i>
2010 October 14th	List of Governmental bodies financed by Government and listed for closure is leaked to press. ILF is included on the list.	<i>No formal consultations, no attempt to monitor potential impacts, no attempt to look at projected future impacts on independent living or increases in institutionalisation for disabled people by local authorities or central government</i>
2010 December 13th	Written ministerial statement issued: ILF closes permanently to new applicants states that following informal discussion with disability organisations, other Government departments and ILF Trustees government views ILF as 'unsustainable'. Statement says there will be a formal consultation in 2011	<i>no formal consultation process, no monitoring of equality impacts, no data process put in place to measure impacts on drop in numbers receiving ILF support or any increased institutionalisation, by</i>

		local authorities or central government-no adequate Equality Impact Assessment produced
2012 July	Government publishes response and rejection to calls for a cumulative impact assessment on closure of ILF and savage cuts to disability support from The Joint Committee on Human Rights on the Implementation of the Right of Disabled People to Independent Living	
2012 July to October	Government Consultation on Future of ILF launched-consultation does not give any option of keeping ILF open or providing more funds to ILF, instead asks what can make transition of ILF users easier as they transfer to local authority 'care'. Local authority 'care' provides only the most basic support and cannot be equated with 'independent living'	Consultation process considered unlawful by lawyers acting against the government on proposed closure of ILF in 2015. This view is supported by Equalities and Human Rights Commission who intervened in the case.
2012 December 18th	Written ministerial statement issued: Full Closure of ILF in 2015 announced on basis of consultation: this is despite the fact that freedom of information requests for local authority consultation responses revealed that many local authorities said that ILF users would not gain equitable independent living support packages with local authorities as they did with ILF, would lose support and/or become institutionalised.	The change will affect 18,500 current ILF users across the UK other numbers affected cannot be obtained as no monitoring or definitive data collection was attempted
2013 March 14th/15th	5 ILF users take Department for Work and Pensions to High Court, London, arguing consultation was not carried out legally Outcome expected end of April 2013	
2013 March	Declassified Government documents released from lawyers for Government show the Department for Work and Pensions and the Secretary of State were aware that ILF users would lose financial support under transfer of ILF users to local authorities and thus lose their right to live independently according to article 19. Documents also show that any money to local authorities for transfer of ILF users to local authority 'care' would not be ring fenced, that institutionalisation could be expected, and there are only transition funds for one year after 2015.	

Summary

The Government have effectively removed the right of disabled people and ILF users (18,500 at 2013), those prevented from applying for ILF from 2010 (no government or local authority data instigated), and those disabled people in the future who wish to employ personal assistants to independent living (no government projections have been attempted or instigated). The Government have failed to provide adequate Equality Impact Assessments, or monitor impacts of

temporary closures, prevention of new applicants or changes in the eligibility criteria of ILF that they have imposed by refusing to fund the ILF adequately. There are currently no publically available copies of any parliamentary regulations on any changes for the ILF apart from in 2007 where ILF Trust was renamed.

We believe that the UK government, the Department for Works and Pensions and concurrent Secretaries of State as funders and therefore the responsible parties for the UK wide ILF have consistently acted against and without any regard for: Article 4, Article 19, Article 28, Article 31 and we foresee potential breaches of Article 16, and Article 25 of the UN CRPD due to the closure of ILF.

Article 4,3 in that ILF closure to new applicants in 2010 was not subject to any formal UK consultation process, and that the formal consultation processes on permanent closure of ILF for 2015 were not carried out adequately in the UK. Article 19 in that the right to independent living will be further curtailed for ILF users contra to the level the ILF structure allowed, Article 28 in that access to basic rights will be curtailed and/or ended without adequate personal assistance support offered through ILF due to its closure in 2015. As cited by the Equality and Human Rights Commission intervention in the ILF case, that Article 31 was breached in that no adequate evidence gathering, data collection or monitoring was instigated, nor any projected impact data attempted by the responsible Secretaries of State or local authorities at any time regarding ILF changes and temporary or permanent closures. We foresee potential breaches of Article 16 in that institutionalisation can be accompanied by high levels of exploitation, violence and abuse, and Article 25 in that health impacts and health crisis will occur with the closure of ILF and the loss of dedicated personal assistance for ILF users.

We believe that it is wrong for disabled people's rights in the UK to be going backwards rather than the government building on the framework that already exists. This is not perfect but has at least until now provided some protection for independent living and a low but not totally impoverished income level. We believe that there must be state protection for the rights of disabled people with complex and high support needs to be supported to live independent lives

Independent Living in UK

Funding for care and support for disabled people and especially for those with the most complex needs to live independently can come from 3 separate funding streams - social services administered by local authorities, continuing health care administered by NHS and from the Independent Living Fund. Continuing health care is only available for disabled people with a high level of continuing health problems so many disabled people do not and would not qualify for this. Only continuing health care funding is free at the point of delivery and other types of social care provision are charged for, although how charging policies apply varies widely between local councils and devolved governments.

Background to the Independent Living Fund (ILF)

The Independent Living Fund (ILF) is an Executive Non-Departmental Public Body of the UK Department for Work and Pensions (DWP) set up in 1988 and is governed by a board of Trustees. There are 2 groups of ILF users – the original Group 1 users who are funded directly by ILF and have never had any involvement with local authorities and Group 2 users who are funded from a newer scheme set up in 1993.

For group 2 users ILF supports users to participate fully in society by paying for support over and above an initial level funded by the Local Authority (LA). It is a national source of funding, assessed at a local level by assessors from ILF, and paid directly to the user. Without the support of ILF most disabled people would receive less support than they currently have due to LA eligibility criteria which may result in more admissions to residential care. ILF when used alone or as a top up to essential support from L.A is an essential resource to support disabled people's rights to opportunities within society the same as non-disabled people.

ILF supports around 18,500 users across the UK and 97p in every £1 of ILF money goes to the user. Without ILF funding Group 1 users in particular (about 6% of ILF users) would be at risk of losing all their funding as they would not in many cases meet the eligibility criteria now in place in most local authorities.

Unlike local authority and health care funding which tends to focus simply on keeping disabled people alive and clean the funding available from ILF helps disabled people to take part in society on an equal basis to non-disabled people. It has enhanced disabled people's equality significantly.

The current cost of ILF is £320 million a year and the average cost of ILF support packages is £346 a week, a tiny proportion of UK government spending. This also compares very favourably to costs in residential care which eg, Winterbourne View (famous in the UK for residents being systematically abused) cost an average of £3,500 per week. The user base of ILF is mostly young disabled people with only 8.7% of ILF users being over 65.

In 2010 just before the Christmas recess of parliament Maria Miller, minister for Disabled People announced ILF was unsustainable and it was immediately closed to new applicants. This was without any consultation with either disabled people or local authorities and was never voted on in parliament and as with the more recent announcement that ILF would close completely it was slipped out just before Christmas at a time when the government thought no-one would notice.

It is impossible to find out what has happened to care and support funding for those excluded from ILF after this date as neither local authorities nor central government have carried out any Equality Impact Assessments nor collated any details of care packages awarded to those who would have previously been able to claim ILF funding. This is an on-going violation of article 31 and article 4.3 both at a national and local level and a failure of both public sector bodies to meet their Public Sector Equality Duties. However in the recent but inadequate consultation on the closure of ILF Local Authorities flagged up the fact that closure from 2010 had resulted in a much lower level of care funding for disabled people not still in receipt of ILF funding.

Article 31 further requires state parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to UNCRPD which has not been done in any way. The government have in fact said to a Joint Committee on Human Rights which called for a cumulative impact assessment of all cuts disabled people are facing that as UNCRPD is soft law they don't have to adhere to it and that the modelling needed for a cumulative impact assessment would be too difficult to do.

DWP have argued that rather than UK government policies working to ensure those with inadequate levels of care and support funding receive more that those who still retain ILF funding to enable independent living should instead lose it so that all are brought down to a lower level of support for independent living. This is in spite of Article 4 of UNCRPD “adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the ... Convention”; to “take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs or practices that constitute discrimination against persons with disabilities”; and – critically in this context - to “**take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes**”; and “refrain from engaging in any act or practice that is inconsistent” with the Convention and “to ensure that public authorities and institutions act in conformity with the Convention” (Articles 4 a, b, c, d).

In spite of the potentially devastating effect of closing ILF on the ability of those with the highest support needs to live independently in the community without any debate in the UK parliament or any vote by MPs the new minister for disabled people, Esther McVey announced on December 18th 2012 that the fund would be closed completely from 2015. All future funding for care and support to current ILF users will be through local authorities only which because of their funding being slashed will not be able to meet these additional costs.

Closure of the Fund breaches the human rights of disabled people as enshrined in the United Nations Convention for the Rights of People with Disabilities, most notably:

- Article 19 – right to independent living
- Article 28 – the right to an adequate standard of living and protection

This announcement followed a very unsatisfactory and inaccessible consultation in which no other option apart from closure was put forward by the government and no details of how people would be supported after the closure of this fund from 2015 were outlined. The consultation analyses fail totally to take into account the opposition to the government's proposals for closure from disabled people, their organisations and even local authorities.

This has allowed the consultation process to be legally challenged and the outcome of the court hearing is awaited however even if this legal challenge is successful this would not in itself prevent the closure of the fund or force the government to make up any funding shortfall to ensure that disabled people's right to live independently in the community were upheld. It would simply slow down the process and force the government to either consult again with more truthful facts or they would have to appeal against the decision in a higher court or they could as they have very recently done in relation to another court judgement introduce retrospective legislation to change the law so they can ignore the court ruling.

During the court case however several documents were disclosed which are devastating in their potential impact upon the rights of disabled people with high support needs to live independently and these show that throughout the consultation period Department for Work and Pensions (DWP) were less than transparent about the future direction of care and support funding in the UK. These disclosures also indicate that the UK government is not working towards improving access to Independent living but in fact what is being suggested will instead be massively regressive and will make the UK go backwards in terms of meeting its obligations under article 19 of UNCRPD.

The main disclosure from these documents which was not part of any consultation process was the fact that DWP only plan to provide any funding to local authorities to meet the additional costs of devolving responsibility for funding disabled people with high support needs after the closure of the ILF in April 2015 for 12 months. So effectively from 2016 this funding will not exist in any form. This was not disclosed to any of the consultation respondents.

DWP also say that on re-assessment by local authorities most users are likely to see a reduction in their current funding levels and that Group 1 users may not be eligible for any funding from local authorities. They suggest that users may have to abandon independent living and spend time in day centres instead, thus removing disabled people from the community and denying them the opportunities to take a full and active part in society.

Further of the 78 local authorities who responded to the consultation 47 of them said for disabled people with the highest support needs closure of the ILF would result in either residential care home admissions (21) or significantly reduced care packages which would affect their ability to live independently and enjoy any quality of life. (26 however this included the single response from London Councils which responded on behalf of all 32 London councils). Numerous others simply said there was not enough information for them to make any reasoned response.

DWP have said that ILF is financially unsustainable yet in these documents they say that closing ILF will cost an extra £39 million and cannot be seen as value for money.

Institutionalisation arising from changes to ILF in 2010

It is impossible to monitor any increase in institutionalisation for those who may have been entitled to ILF before changes in 2010 to new applicants. As noted neither the Government nor local authorities carried out any monitoring, data collection or follow-up of these groups. However, an analysis of local authority responses to the ILF consultation showed that 84.5% agreed that the full closure of ILF would mean that disabled people would not have their needs met on a like for like basis by the local authority compared with ILF support with many saying that the full closure of the fund would lead to greater levels of institutionalisation. It is therefore logical that the ILF closures to new applicants in 2010 would have been judged by local authorities to have had the same impact on disabled people prevented from applying to ILF. Consultation responses from disabled peoples' user led organisations, also noted the effect of increasing institutionalisation of those affected by changes in 2010 in the context of ongoing cuts to local authority funds.

One local authority, Kent County Council, did identify those who would have been eligible for ILF in 2010, but purely in financial terms and impact on local authority budgets. This gives some indication of the difficulties that local authorities were facing in a time of budget cuts::

The closure of the ILF to new claimants from June 2010 (confirmed as final in December 2010) has already had a significant financial impact on Kent

County Council. There are currently nearly 500 of our clients who might have qualified for the ILF had it not closed to new claimants. The annual cost of their care and support which has to be funded only by the local authority (with a small contribution usually from the client) is approximately £25 million. If we assume that between 35% and 50% of this cost might have been met by the ILF had it been available (as indicated by ILF analysis 1), this represents an extra £9-12 million per annum that has to be funded by KCC

Please see section 7 point 2 for further details on budget cuts to local authorities

Legal/administrative changes

No legislation has been put before the UK parliament which Members of Parliament (MPs) or Lords could vote on and there have been no discussions held in parliament about the plans to close the ILF. This was instead simply announced by the minister for disabled people both in relation to new applicants in 2010 and to existing applicants in 2012. The documents disclosed during the court hearing show that DWP plan not to apply to the Treasury in the next round of the Spending Review for any further funding to make available to support the continuation of devolved funding to local councils and devolved governments. We assume that these changes are being made through secondary legislation but if anything has been documented then there seems to be no public record available.

The trustees are not in favour of the fund closing from 2015 as they have expressed concerns that this will not be possible and will be harmful for existing users who as trustees they have a duty to protect.

Impact of Changes on disabled People

ILF users because of their impairments seem to die comparatively regularly. In 2010 there were 23,000 fund user and now just over 2 years later there are only 18,500 users.

However the impact of the closure of the fund will affect very negatively the right to live independently for those with the highest support needs. We already know of situations where continent disabled people are having overnight care removed and instead being left with packs of incontinence pads (Kensington and Chelsea council in particular) or have been told they should be catheterised (Manchester council). In Worcestershire the council have recently introduced a Maximum Expenditure Policy which aims to limit the total amount any disabled person can get each week for their care and support. If their needs are higher than this cap the local authority has said they will either have to go into residential care homes or find additional funding themselves.

In fact not having the right to even go to the toilet when they need to seems to be one of the main fears that current ILF users have. The UK is the 7th richest nation in the world and in the 21st century we believe that its disabled citizens should not be left with packs of pads and without even this most basic aspect of support. (see case studies at the end).

I have outlined what has happened earlier and the way in which the government failed to meet their Public Sector Equality Duty has allowed the consultation process to be legally challenged supported with an intervention from the Equality and Human Rights Commission.

The documents disclosed during the court case illustrate that the UK government is not in any way working towards improving access to Independent living but in fact what is being suggested will instead be massively regressive and will make the UK go backwards in terms of meeting it's obligations under article 19 of UNCRPD.

The numbers of disabled people in the UK population who are defined as severely disabled is 2% yet according to figures from : 'A Fair Society?' Centre for Welfare Reform, January 2013 this group of people will face 15% of all cuts to their incomes.¹

Other events/ circumstances involved in the situation

There are 2 main factors also involved with the plans to close the ILF, a draft Social Care Bill and the massive reduction in funding for care and support that local authorities have faced and will face in the next 2 years.

Draft Social Care Bill ²

which is now set to come into force from 2016. This however does not in any way address the provision of care for disabled people of working age, and nor does it address how those who are over pension age and already in receipt of care funding to live independently will continue to get that funding or the necessary level of care and support they need.

¹ <http://www.centreforwelfarereform.org/uploads/attachment/354/a-fair-society.pdf>

² 40 Department of Health (2012) Caring for Our Future: Reforming Care and support: <http://www.dh.gov.uk/health/2012/07/careandsupportwhitepaper20>

Local Authority Care in Crisis

Under the previous Labour government there was an Independent Living Strategy based on the concept of personal budgets with money being given to service users to give disabled people greater choice and control over the care and support they had to live independently. This meant that rather than services being commissioned for disabled people they would get the money themselves and be able to purchase what services they wanted. To date this system has been very patchy and implemented differently throughout parts of the UK. In Northern Ireland and Wales there has been little progress with implementing personal budgets and the same is true in some local authorities.

The other problem is that what level of care and support people can get varies between each local authority as they can decide for themselves where to set funding thresholds and apart from ILF funding there is no nationally transportable care system. Even ILF funding depends to some extent upon local authority eligibility criteria as to be eligible for ILF you have to be in receipt of a certain level of care funding from your local authority first. (with the exception of Group 1 users.)

Assessments for local authority care are based on Fairer Access to Care Services (FACS) criteria and originally there were 4 levels of care funded, low, moderate, substantial and critical. In 2005 50% of councils in England (152 in total) funded care for those with moderate needs and above but by 2012 83% of these were only providing services to those with substantial or critical needs.³ In addition many local authorities do not fund overnight care even for those who need it and this is currently funded either through continuing health care or through ILF.

This tightening of eligibility criteria is supported by the budgetary report from Association of Directors of Adult Social Services (ADASS) which found that 83% of councils now fund only substantial and critical needs an increase of 6% since 2011-12 and 2% only fund critical. Those figures however ignore councils where they have introduced eg. greater substantial criteria.⁴

What can be funded through FACS criteria is restrictive and very different from what can be funded through ILF funding.

Already Local authority budgets have been slashed and adult social care funding in England was cut by £991 million by 2011 and a further £890 million by 2012. Children's social care in England was cut by £1.852 billion from 2010 – 2012⁵. Local government budgets overall are further set to be cut by another 28% in 2013-15. As austerity results in cuts to local authority funding social care funding is already at breaking point even without the loss of ring-fenced ILF funding.

Even disabled people who are still in receipt of ILF funding have been affected by these cuts in 2 main ways. All ILF recipients are asked to contribute half of their Disability Living Allowance (£37.50 per week) towards the cost of their care package and those getting Income Support are also asked to contribute the portion of this which is the Severe Disability Premium (approximately £75 a week). Prior to 2010 if people couldn't afford to pay this they could ask for their contribution to be waived but from 2010 this cannot be done anymore. Further due to care cuts at local level anyone whose care needs have increased are having great difficulty getting any additional care funding from Local Authorities and they are also unable to get any extra funding from ILF.

Many local authorities have said in their consultation responses to the closure of ILF that they will be unable to fund equivalent support and that some people may lose their entitlement to support

³ Age UK (2012) Care in Crisis 2012:

http://www.ageuk.org.uk/Documents/EN-GB/Campaigns/care_in_crisis_2012_report.pdf

⁴ http://www.adass.org.uk/images/stories/Press12/ADASS_BudgetSurvey2012Summary.pdf

⁵ : 'A Fair Society?' Centre for Welfare Reform, January 2013

<http://www.centreforwelfarereform.org/uploads/attachment/354/a-fair-society.pdf>

altogether. Local authorities who have had budgets cut by central Government and are also cutting back on support generally are looking at institutionalisation in care homes as a cheaper option in a number of cases. This is a step backwards for disabled peoples' rights.

A recent SCOPE (large disability charity) report into care funding found 105,000 disabled people risk losing vital social care and support. These are not people who would qualify for ILF funding since the end of the initial Group 1 fund. Since 2008 90,000 or 1 in 6 fewer people are using social care.

The report says rationing of care and support has already left many disabled people at crisis point – and the negative impact on their lives is growing.

New evidence from our survey shows that disabled adults:

- are failing to have their basic needs met: with nearly four out of ten (36 percent) unable to eat, wash, dress or get out of the house due to underfunded services in their area.
- are withdrawing from society: with nearly half (47 percent) saying the services they receive do not enable them to take part in community life and over one third (34 percent) being unable to work or take part in volunteering or training activities after losing support services.
- are increasingly dependent upon their family: with nearly four in ten (38 percent) seeking support services saying they experienced added stress, strained relationships and overall decline in the wellbeing of friends and family.
- are experiencing isolation, stress and anxiety as a result: with over half (53 percent) saying they felt anxious, isolated, or experienced declining mental health because they had lost care and support services..⁶

As a disabled person whose care had been reduced told the survey:

“The social worker said if I couldn't get 24 hour care in my own home I'd be forced into residential care against my will. I feel suicidal at the thought of losing my home and freedom. My basic human rights are being denied. I'm devastated.” Thomas

Underfunding has already resulted in many younger adults ending up in inappropriate residential care services meant for older people. ⁷ In 2009, of the 24,000 young adults with physical disabilities living in care homes, it is estimated that around 9,000 were inappropriately housed, often in residential homes for the elderly.⁸

These are testimonies from around the UK of how disabled people will be affected by the closure of the ILF.

Mary - “ I have seen what my care package would look like without the ILF contribution. Per day, I would receive support for a carer to sleepover, then 1 hour support for lunch, and 1 hour for tea.

⁶ http://www.scope.org.uk/sites/default/files/The_Other_Care_Crisis.pdf

⁷ Ibid from When the Loving Care Stops, The Telegraph Online, 2 September 2012, Cherrill Hicks, <http://www.telegraph.co.uk/health/9515657/When-the-loving-care-stops.html>

⁸ Ibid New Philanthropy Capital (2009) Rights of passage: Supporting disabled young people through the transition to adulthood, <http://www.thinknpc.org/publications/transition-of-disabled-young-people>

Per week would be added 7 hours for social activities, 90 minutes for shopping, 45 minutes for housework and 20 minutes ironing, plus 2 support slots of 15 minutes each for showering.

With nothing but a Local Authority care package I would have a future of nothing more than sitting in my wheelchair from quarter to eight in the morning until half past ten at night with only two breaks, at lunch time and at tea time. Without support to go to the toilet between visits from a care assistant I would be wet, so when the care assistant did come for the hour lunch time and tea time would need to be taken to clean me. I would also get a sandwich, a hot drink and be toileted. At tea time instead of a sandwich I would get a warmed up meal, which would have to be a microwave meal because no time would be allowed in my support package for cooking.

By the time the night staff came on at ten, I would be wet again and need to be washed and changed as well as been given a hot drink and put to bed at half past ten.

Being left wet for so many hours every day would lead to open pressure sores which would need to be treated by a nurse on a regular basis.

My day would be nothing more than me sitting in a wet pad, just being fed and watered, no freedom to do anything I wish. My home will be my prison.

Oh except for my 7 hours of social care per week. Well with that I could use it to have one day out of the house per week or I could add 1 hour per day to my lunch or tea time call to make it less rushed.

The other alternative would be a care home. Would the people who are taking my ILF away want to live in a care home where they'd be at much greater risk of abuse? "

Sophie - The work my PAs do: They do everything, everything physically that I can't do for myself, so it's all aspects of personal care, you know - like me getting up, going to the loo, washing, dressing, cooking for me, cutting my food up, cleaning, laundry, driving me in my van. I still need the same levels of assistance whatever I'm doing, so if I'm working or round at a friend's house, I need them with me, to, you know do all those things.

On being forced into a carehome: It's too scary to even contemplate to be honest with you. No, it's just like - that's not on my radar. It's just not going to happen. We have to ensure that that does not happen. We can't go back 30-odd years. It's just not going to happen. It's just not happening.

That's the irony as well, because actually, even if they deported us all tomorrow to some sort of home, homes don't provide those levels of care. That's why we had the ILF - because our needs are high. You know, people in residential care, they're sitting around all day waiting to go to the loo and all the rest of it.

I am a bit obsessed with going to the loo - but it's just, that's a core vital thing and one of the thing that... local authorities have never been keen on funding people's night time packages and you know, one thing that's been said, including to me in the past, but also recently - I know one young disabled woman that although she's not incontinent, [she's been told] she should use incontinent pads at night. Seriously.

I think there's that idea there as well that if you try really hard, you can do something. Well, I can try as hard as I like but I ain't walking, I cannot get myself on and off the loo. Fact. Deal with it. Get over it. Something that has worked for so long so well why are they doing this?

Father of ILF user - "My Son's care package comes to over £50,000 per year of which the ILF package makes up over £23,000. The Local Authorities "Indicative Budget" maximum level for someone living at home is £31,094 so without ILF his total care package would be slashed by almost 50% and leave it impossible for him to manage to live at home".

Anne "As half my care package is ILF I would first have no control over my toilet needs, this may result in me being catheterised. I am not unable to get out of bed or in bed myself, nor can I dress myself. I need support in all personal care needs, including keeping clean etc. I would not be able to attend any meetings when various government and NGOs ask me to be part of their various consultation plans. I would have no control over what time I got up or what time I went to bed therefore I would have no social life whatsoever. When ILF finishes in 2015 I will not have any social life. This will mean I will not be able to visit friends, attend the cinema or theatre, go to my bridge club or attend a primary school to assist children to read. I will no longer be able to use my car for shopping taking my dog to the woods etc. Having campaigned for the last 26 years this will end as I need support to do this. I regularly attend course on photography and employment issues – these will not be possible without ILF funding."

Roxanne - "I am 27 years old female, and I currently live in my own flat, with 24 hour PA's who I have directly employed. I have had various levels of funding from ILF, ever since becoming an adult. It has meant that I was able to live on campus at the University of Warwick, where I completed a BA in History and an MA in Modern British History. I was then forced to move back to my family home, because I did not have the high level of support that I need, and I have only recently been able to start living independently in the community, with funding from my local authority and ILF. This amount was not as much as would have previously been the case because a freeze was put on the amount that they, ILF, could contribute to disabled people's care packages in April last year, before my current care package was agreed. As a result, I was only entitled to receive the same level of funding that I had been awarded in my previous, much less expensive, care package. This meant that my local authority was put under increased pressure to fund my entire care package, and after the ILF is abolished, it seems very likely that all local authorities will find it difficult to provide care for severely disabled people living in the community. I have had to really fight against my local County Council in order to get funding for my current care package, but what scares me is that although I will always be disabled (and actually, my needs will increase in time), there is no kind of guarantee that I will receive my current care package even past my next review. "

Charles - I am a 44 year old digital artist/editor & film maker, a lot of time is spent travelling to locations for shoots, I can't imagine how I would manage without ILF which funds a third of my care package.. to lose such vital funding will probably change my life in a way presently I do not want to think about, however, as the government is pushing this legislation through regardless, I have to consider my position. Ultimately I fear that any real & significant control in my life and how I presently choose to live my life will be significantly curtailed. I know in this present political climate, any changes will be presented to the general public in a way that suggests no "significant" change, "the disabled" are worrying needlessly etc, but the reality has to be heard. I will have to make my PA's redundant, relying on goodwill of friends or volunteers would not be feasible. I would lose control of my life.

Gabriel - I am a 40 year old ex archaeologist, living in busy East London, and it would be impossible to manage if I lost my ILF. This funds 50% of my care package, so the loss of ILF would mean that I would lose my independence. At the moment I live independently and use my ILF to maximise my independence, to access the community, to do voluntary work in three different places. This government has pushed legislation through in a way which challenges human rights. Without ILF I would lose my home and my independence and would be forced to rely on my aged father and sleep on his floor as his house is inaccessible.

Susan - I am 39 years old and my ILF contributes roughly 25% to my 24/7 package. It is thanks to the ILF that I have been able to study at University, become involved in voluntary work and, more recently, have been able to hold down a full time job in a disability organisation, helping other people make the most of their care packages. The ILF has allowed me to contribute financially to the economy yet there

are many more people who, thanks to the ILF have made contributions to society that are every bit as important, and often times more, than my one contribution. In a time where disabled people are classed as undeserving scroungers it is vital to point out these invaluable contributions and also to not that, without ring-fenced funding that affords people more than survival care we will be forced into a position where we can't give back to society. I have already seen this in my line of work where people who would have benefited so much from funding from the ILF are just left with a couple of visits a day – literally for “feeding, watering and toileting” – of course there is no willingness by Social service to put that extra little bit in any more, as they know that the ILF won't be there to part fund! This is a real disgrace. Personally, any negative change to my care package will have not only a severe affect on me, but also on the 6 people that I employ as Personal Assistants. The loss of the ILF really is a return to the dark ages!

Jenny “I can't bear to think of a return to life” without the opportunities the ILF has given her. “Before I was referred for funding from the ILF I received a package of 4 hours a day, one hour for getting me up/showered and breakfasted, one hour for house work and lunch, one hour for supper and an hour to do the “put to bed”. In between times I couldn't get a drink or use the toilet- let alone do anything meaningful with my life.” With support funded by the ILF she was able to go to university, get a full time job and become a Trustee of a charity.

Mother of ILF user - Jane has Downs Syndrome. In some ways she appears to be quite a capable lady, but has a severe learning disability and also and most importantly has severe health problems which could prove life threatening if not handled immediately and in the correct manor.

Karen has a profound mental and physical disability. She is mostly a happy lady but with no means of communication other than her body language.

Jane and Karen's families have come together with the help of their local learning disability team and have enabled them to live in an apartment together, for the past 4 years, with the care of personal assistants 24/7, employed directly by them using funding from the Independent Living Fund. The ladies both live very productive and worthwhile lives together accessing activities in the community and interacting with everybody they come into contact with.

This is exactly what the Independent Living Fund was intended for and Jane and Karens' lives have improved considerably. They have a future to look forward to rather than spend the rest of their lives in a care home

Why the ILF court case is likely to show chances for reversing the government decision on the closure of ILF are nonexistent.

A written statement from Louise Whitfield, head of casework Public Law Project; Pierce Glynn (now Deighton Pierce Glynn Solicitors) 2009; partner 2011 and one of the solicitors acting in the ILF case.

Louise is a public law specialist, with 14 years' post-qualifying experience of conducting high-profile judicial review claims across a wide range of subject areas including discrimination and equality duties, public sector funding and procurement, medical services and community care, claims based on breaches of the Human Rights Act, and claims relating to inquests and prisoners' rights. Louise is highly recommended in administrative and public law and is recognised as a leader in the field of administrative and public law, as well as civil liberties and human rights.

“The UK legal system's mechanism for challenging government decisions only has scope to look at the decision-making process, not the merits or substance of the decision itself. Thus when challenging government attempts to curtail ILF, the courts will not consider whether this is the right

step for the government to take in terms of disabled people's rights to independent living, or even whether this will adversely affect disabled people; this is not a matter for the court, which would perceive this issue as a political decision for government.

The corollary of this is that if the court finds that the decision in December 2012 to close ILF to current recipients was unlawful (because of the flawed decision-making process) and quashes that decision, the government is highly likely simply to re-run its decision-making process addressing the flaws identified by the court (such as an inadequate consultation process), but reaching the same ultimate result – a decision to close ILF to current recipients. This would result in a lawful decision to go ahead with the closure, which could not be challenged further by legal proceedings.

In addition, a breach of the UNCRPD is not directly enforceable through the UK legal system. The Convention is a very important and highly relevant interpretative tool as set out in the submissions from the Equality & Human Rights Commission which intervened in the case, but a breach of the Convention itself would not lead the court to rule that the decision to curtail ILF was unlawful on that basis alone.

The reliance on local authorities to fund social care exclusively is particularly problematic given that they can take into account their resources when deciding what level of needs to meet and how those needs should be met (see elsewhere in this submission where we have provided examples of continent people being given pads rather than night-time care). This point – whether resources are relevant or not – has been unsuccessfully challenged in the UK courts several years ago (*R v Gloucester County Council, ex parte Barry*, a decision of the House of Lords dating back to 1997). With the closure of ILF there will be even more pressure on local authority budgets, recognised by the local councils who responded to the ILF consultation clearly stating they would struggle to meet disabled people's needs in terms of their current arrangements. The fact that they can take into account their resources and that this cannot be challenged fundamentally undermines the right to independent living.”

Grave and Systematic Violations

Disabled people across the UK are enduring grave and systematic violations of their right to independent living through the closure of ILF at the national levels, savage cuts to social services budgets at the local levels, and a raft of measures to reduce what is seen as the economic 'cost' of supporting disabled people by the UK government, as well as the cessation of legal aid to contest any failings in benefit claims from April 1st 2013.

All are taking place in a context of escalating applied austerity measures to long established individually supplementary benefits payments to pay for the extra costs of being disabled to disabled individuals. These measures include the abolition of the disability living allowance (estimated 600,000 affected⁹), severe disability payments and the imposition of the much maligned Employment Support Allowance which has undergone a series of test question alterations since 2009 through the Work Capability Assessments to further tighten criteria to access funds under its system and the new rules that all claimants must pay a percentage of council tax on their homes from April 1st 2013. In addition, changes in how housing benefit is applied (from April 1st 2013) are currently leaving many (estimate 420,000¹⁰ affected) disabled people fearing homelessness and/or forced eviction from their homes, as additional penalties for bedrooms which are deemed unoccupied mean that disabled people face paying extra costs. The government gives the option that people can move, but this is less likely for disabled people due to the limited stock of accessible housing and the possible need for adaptations in their homes, or the need to remain in an area and home known to them.

⁹ <http://www.disabilityrightsuk.org/news/2013/march/will-you-be-squeezed-pip>

¹⁰ <http://www.disabilityrightsuk.org/policy-campaigns/benefits>

While a number of domestic court cases are being brought in an attempt to tackle various aspects of all these changes through judicial reviews, there is no doubt that all reforms are having a severe and systematic impact on the right to independent living.

The cuts to social service budgets have led to domestic court cases against both tightening eligibility criteria to any support from local authorities and the inhumane situations in which disabled people are being placed in by these cuts. For example the case of Birmingham City Council (2011) which attempted to raise eligibility for social care to the status of super critical¹¹ and the case of Elaine McDonald (2011) who was denied funds for night time care and forced to wear incontinence pads, despite the fact that she was not incontinent¹². The first case was successful, but the second was not, resulting in the practice of Kensington and Chelsea local authority's budgetary 'solution' spreading to other local authorities. In the case of R v Gloucestershire County Council ex p Barry [1997] 2WLR 459 in which Michael Barry was in receipt of home care services from the Council who decided in September 1994 that, because of government cuts, it would have to withdraw the services. About 1500 service users were similarly affected. The services were provided under section 2 of the Chronically Sick and Disabled Persons Act 1970 which requires local authorities to provide or make arrangements for certain services where it is satisfied that it is necessary to meet the needs of a disabled person to do so. The House of Lords judgment in the case of R v Gloucestershire County Council ex p Barry [1997] 2WLR 459 was an agonisingly close 3-2 decision in favour of the Council. This meant that councils or local authorities could take into account their resources in decisions of whether to withdraw or limit care services. The continuing crisis has forced other local authorities to bring in policies of 'economic caps' or 'maximum expenditure policies' (2012) which state that those disabled people whose 'care' costs rise above a certain amount will be placed into residential institutions¹³. Therefore the closure of ILF and transfer to local authority schemes is a matter of fear for current ILF users.

ILF Closure and further Impacts on Independent Living

It is in this climate that the UK government closed the ILF first to new applicants in 2010 and then announced the complete closure of ILF in 2015 on the basis that it was 'not sustainable'. However running costs for ILF are 2% while those of the local authority are an average 16%. As we have illustrated the government has consistently failed to monitor trajectories or develop any data on those who were prevented from applying for ILF nor has it carried out any projections for those who will lose crucial support to lead independent lives when the ILF closes in 2015.

The 2010 closure to new applicants was not accompanied by any formal consultation process¹⁴ which would have allowed an earlier and more considered process into alternatives. However, the government instead proceeded to undertake a flawed and legally challengeable consultation exercise around full closure of ILF in 2015. It did not follow its own processes in developing adequate equality impact assessments, at times refusing to see the need for them at all. The Equality and Human Rights Commission (EHRC) which intervened in the ILF case stated quite clearly in their case intervention that:

The court not only may, but must, take the relevant provisions of the UNCRDP into account when interpreting the domestic legislation, and in particular, when assessing whether a public authority has complied with the public sector equality duty and Articles 8 and Article 14 ECHR. The requirement to do so is enshrined both in national and ECtHR

¹¹

<http://www.campaignforafairsociety.com/2011/04/disability-groups-force-council-to-back-down-over-plans-to-set-super-critical-eligibility-threshold/>

¹² <http://www.bihhr.org.uk/news/bihr-comments-on-supreme-court-ruling-in-mcdonald-v-kensington-and-chelsea>

¹³

<http://www.irwinmitchell.com/newsandmedia/2012/december/Family-Takes-Legal-Action-Against-Worcestershire-Cou-nty-Council>

¹⁴ <https://www.whatdotheyknow.com/request/153382/response/378204/attach/html/2/FOI%201278%20response.pdf.html>

caselaw.

UNCRPD Articles cited by the EHRC in court included: Articles: 1, 2, 3, 4, 5(3),5(4), 19 and 31

As previously noted, the process of the court case to challenge the ILF consultation released DWP correspondence documents between the DWP and Secretary of State that identified the government did not foresee the closure of ILF as gaining any significant media coverage. In addition, these documents also revealed that both the DWP and the Secretary of State were perfectly aware that ILF users would lose some or all of their support when ILF was transferred to local authorities in 2015. However, a hypocritical publicity strategy had also been documented which talked of 'choice and control' within a more equitable process, when in reality it was clear to both parties that the closure of the ILF would result in a loss of 'choice and control' and increase inequalities for disabled people. Along with the catalogued events documented here we feel this shows the UK Government exhibiting a historically unrivalled level of contempt for disabled people, article 19 and for the UNCRPD

The UK government has also refused to carry out a cumulative impact assessment on the impacts its combined actions are having on disabled people's right and enjoyment of independent living as requested by the Joint Commission on Human Rights. In the same report of 2010-2012, and prior to the announcement of the full closure of ILF in 2015 the Joint Commission on Human Rights stated:

The range of reforms proposed to housing benefit, Disability Living Allowance, the Independent Living Fund, and changes to eligibility criteria risk interacting in a particularly harmful way for disabled people. Some disabled people risk losing DLA and local authority support, while not getting support from the Independent Living Fund, all of which may force them to return to residential care. As a result, there seems to be a significant risk of retrogression of independent living and a breach of the UK's Article 19 obligations¹⁵.

We have aimed to provide events, figures, and case studies here, and have attempted to articulate the apparent inability of the UK government to promote, adjust to, effectively monitor or pay heed to the principle and spirit of article 19 and the UNCRPD particularly in relation to independent living and the closure of ILF.

We submit that taken in isolation: the closures of ILF, the budgetary cuts to local authorities and social care, cuts to housing benefit, the abolition of disability living allowance, removal of legal aid, the imposition of the work capability assessment and other changes have produced violations of the spirit of UNCRPD, yet that taking account of the cumulative effects of all these changes, that the UK government has committed grave and systematic violations of the spirit of the UNCRPD and contra article 19

In relation to the closure of ILF we hope to have provided enough clear evidence to show grave and systematic violations of Article 4, Article 19, Article 28 and Article 31. We foresee future violations of Articles: 16 and Article 25.

Above all, we agree with the Joint Human Rights Commission and contend that their stated 'significant risk of retrogression of independent living and the breach of the UK's Article 19 obligations' has now become a factual reality in the UK.

15

<http://www.publications.parliament.uk/pa/jt201213/jtselect/jtrights/23/23.pdf>

ILF and Independent Living: actions by UK Government as a breach of the UNCRPD in the UK

Working with unions at the ILF we have been told that nothing the government are now doing (as they are pressing ahead with their plans to abolish the ILF regardless of waiting for the outcome of the court case) will be irreversible before the last few months in 2014.

1. We would ask that the Committee launch an urgent enquiry into the loss of the right to live independently in the UK and urge the government to at least devolve funding which should be ring-fenced to ILF users for their life-time if they go ahead with the planned closure of the fund.

2. Given the crisis in adult care funding at local authority level we would urge the committee to investigate how adequate and affordable access to care and support funding will be provided now and in the future particularly for those who have been unable to access ILF funding from 2010 and who now have no access to a legal solution to this.

As stated, we believe that the UK government, the Department for Works and Pensions and concurrent Secretaries of State as funders and therefore the responsible parties for the UK wide ILF have consistently acted against and without any regard for: Article 4,3, Article 19, Article 28, Article 31 and we foresee potential breaches of Article 16, and Article 25 of the UN CRPD due to the closure of ILF.

Article 4,3 in that ILF closure to new applicants in 2010 was not subject to any formal UK consultation process, and that the eventual formal consultation processes on permanent closure of ILF for 2015 were not carried out adequately in the UK allowing it to be challenged in the domestic law courts.

Article 19 in that the right to independent living will be further curtailed for ILF users contra to the level the ILF structure allowed and in the context of ongoing budget cuts in the UK

Article 28 in that access to basic rights will be curtailed and/or ended without adequate personal assistance support offered through ILF due to its closure in 2015.

Article 31 As cited by the Equality and Human Rights Commission intervention in the ILF case, that Article 31 was breached in that no adequate evidence gathering, data collection or monitoring was instigated, nor any projected impact data attempted by the responsible Secretaries of State or local authorities at any time regarding ILF changes and temporary or permanent closures.

We foresee potential breaches of

Article 16 in that institutionalisation can be accompanied by high levels of exploitation, violence and abuse and

Article 25 in that health impacts and health crisis will occur with the closure of ILF and the loss of dedicated personal assistance for ILF users.

We further argue that all disabled people that will be affected by the permanent closure of ILF in 2015 have already been affected by ongoing budget cuts; especially at the local level of the local authority thus preventing a comparative experience of independent living outcomes available under ILF. These factors are combined with a vast range of applied benefit cuts targeting disabled people that have exasperated this context elevating them to severe and grave implications for disabled peoples' right to independent living in the UK.

