

The Future of the Independent Living Fund

Disability Rights UK consultation response

October 2012

Background to this response

Disability Rights UK was formed in January 2012 from a merger of Disability Alliance, the National Centre for Independent Living and Radar.

We aim to be the largest national pan-disability organisation led by disabled people. Our vision is of a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

Disability Rights UK's objectives are:

- To mobilise disabled people's leadership and control;
- To achieve independent living in practice;
- To break the link between disability and poverty; and
- To put disability equality and human rights into practice across society.

We believe that the Independent Living Fund (ILF) has supported disabled people to achieve these objectives at an individual level. We are nervous of the future support arrangement for disabled people who would have qualified for ILF – especially in the context of councils restricting social care access.

Our member organisations raised concerns about the future of the ILF during our regional events. Some local organisations, including the Wiltshire Centre for Independent Living has outlined its belief that the plans could be 'catastrophic' for some disabled people.

We have met with some members to discuss the Government proposals as well as surveying member organisations and individuals' views. We are very grateful to our members and other individual disabled people for providing us the views and experiences that have shaped this response.

Responses to our survey on the Government plans

Almost 140 people responded to our survey, which included the Government questions as well as some focused on our concerns/suggestions. This

included a large percentage of ILF users – 64% of respondents were current ILF recipients (36% were not). However, of those who were not currently receiving ILF, 61 believed that they would have qualified for ILF support had the Fund not been closed to new applicants in 2010.

As there are now fewer than 20,000 ILF users in the UK (a drop of about 10% since 2010) our survey has managed to reach a significant number of the people directly affected in the relatively short [period of the Government’s consultation.

Responses were received from across the UK – including England, Northern Ireland, Scotland and Wales.

A majority of respondents were 45-64 (almost 53%) years of age with a small sample of people under 24:

Under 16 years of age	0.0%
16-24	5.8%
24-44	29.8%
45-64	52.9%
Over 65 years of age	11.6%

The vast majority of respondents stated that they were disabled people (72%) with a further 26% being family, friends, carers, supporters or other advisor to disabled people. Just 2% of responses were from non disabled people.

Use of ILF

Disability Rights UK believes ILF has supported disabled people to be more in control, independent and better able to contribute; 25% of the disabled respondents who had used or were receiving ILF funding told us that it helped them participate in work, training or education for example.

We provided space for disabled people to tell us what ILF had helped support. Some direct examples are provided below to demonstrate the difference the ILF has made and its importance to achieving independent living:

“Pre ILF I only had 4 1hour visits a day meaning I couldn't even have a drink or use the toilet. With the additional funding from the ILF I have been able to become a trustee...and have entered full time work doing my dream job. I have absolutely no doubt that I would not have been able to do this without the ILF funding!”

“I would not have been adequately supported with day to day tasks. It is unlikely I could continue to work as I need to be able to get ready for work as well as just be there the same applies to college which I have attended part time”

“work volunteer participate in community and social activities”
“volunteering as a counsellor at a disability organisation...Studying at local college...Taking part in Power Chair football”

“I have been in receipt of ILF for over 20 years. Had I not been receiving ILF I might have had to give up my work and even be moved into residential care, in particular when my mother died”

“I would be stuck in the house 24/7. I'm a wheelchair user and don't drive”

“Without ILF support I would not be able to live independently. I would not have control of what I do and where I go. I would not have a choice of who meets my care needs. I would not have a choice of what time my care needs are met. I would not be able to see family”

We believe the purpose of support should have formed a larger consideration in Government plans to change the ILF. The aims and vision of the ILF have been critical to how it has supported disabled people and, whilst it is imperfect as a model, disabled people's user satisfaction levels are very high (especially when compared with local authority alternative provision) and the ILF has helped deliver the personalisation agenda and supported disabled people to take control and live independently.

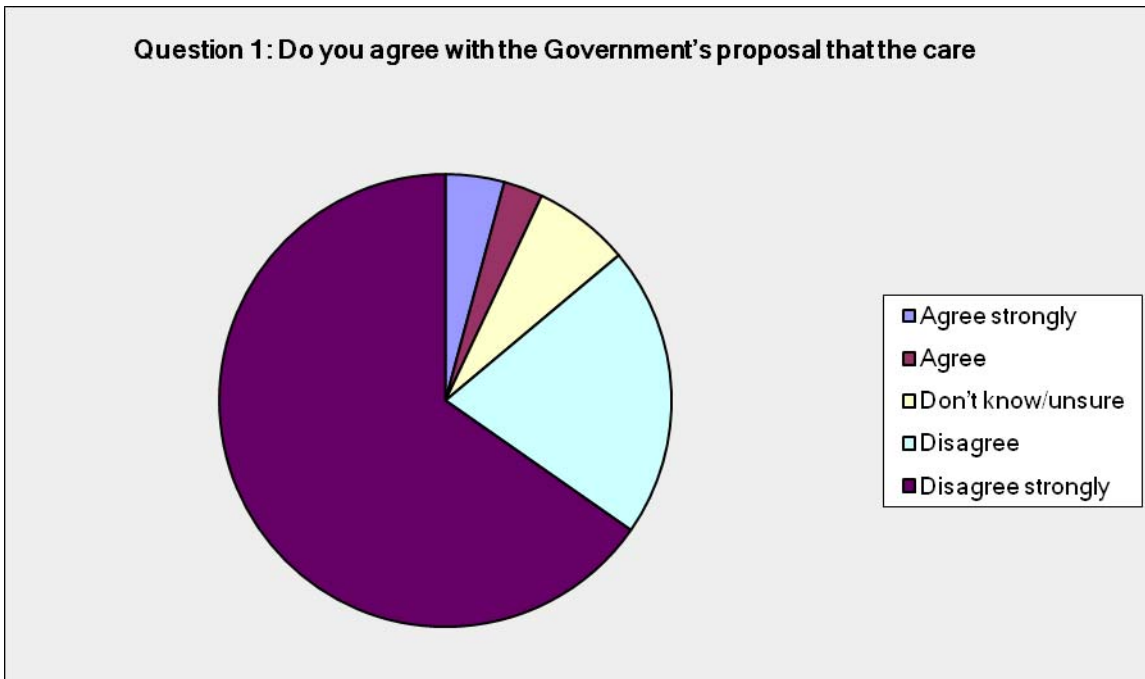
Disabled people are fearful of a back-slide in rights and control under current proposals – especially in a climate of cuts across the board with a further £10 billion of service and benefit cuts now on the horizon. It is essential that the Government meet its obligations towards disabled people – and aspiration to ensure that disabled people with the highest needs continue to be able to access support.

Survey responses to Government consultation questions

We asked respondents the questions set out in the DWP ILF consultation. The responses are summarised in this section of our response.

Question 1: Do you agree with the Government's proposal that the care and support needs of current ILF users should be met within the mainstream care and support system, with funding devolved to local government in England and the devolved administrations in Scotland and Wales? This would mean the closure of the ILF in 2015.

The responses were every clearly opposed to the Government plans. Just 7% agreed that the suggested approach was appropriate – with 86% disagreeing with the proposals (the remaining 7% were unsure):



Question 2: What are the key challenges that ILF users would face in moving from joint ILF/Local Authority to sole Local Authority funding of their care and support needs? How can any impacts be mitigated?

Responses varied but can be grouped around the following issues: funding; local authority rigidity in use of resources and an associated lack of control; reduced independence; and the individual's ability to navigate any new system.

- Concerns at funding and existing care service retraction under council control:

“Local councils are already cutting care so where would the extra money come from?”

“My independence, choice and control will be threatened if funding is solely provided by my Local Authority. My Local Authority’s budget is over stretched, in response it has already cut disabled people’s care in my area to a bare minimum. It is likely that my ILF funding will be cut in a similar way when responsibilities are transferred to Local Authorities. Without additional ringfenced funding for LA’s to maintain ILF users support packages I fear that my support will be severely reduced”

“ILF funding needs to be ring-fenced for ILF users within Local Authority budgets, so that it does not simply disappear immediately into general coffers”

“There is not enough detail or information in the consultation to comment on this, I fear the funding would not be ring fenced”

Local authority responses to our survey and in other meetings have demonstrated a similar fear about receiving sufficient resources from central Government to meet demands. Directors of Adult Social Services have also previously highlighted the need for ring-fenced budgets and the Government should explore this option for at least the ILF portion of grants if the proposals are implemented.

- Restrictive criteria for using local authority resources, diminished independence:

“Social services are out of touch with what young disabled people need to live a happy and fulfilled life”

“more restrictions in living an independent life...unable to use for improving life eg attending college, training, attending gym, social activity”

“local authorities will not provide flexibility in use of funding currently available under ILF support”

“For my father the biggest worry is that the council will put him in a home because it costs them more than if he were to live in residential care, so in that sense we fear that the council won't be flexible in the use of funding, as is currently the case”

- Ability to understand new processes or systems:

“ILF users need to know what any new care and support infrastructure would be and how to access it. They also need to know what impact any new assessment of their care and support needs would mean, including how any decisions can be appealed...ILF users typically have employment contracts with their employees; these will need to continue with no break in service to ensure that user's needs are met”

Question 3: What impact would the closure of the ILF have on Local Authorities and the provision of care and support services more widely? How could any impacts be mitigated?

Many responses link to similar issues raised in Question 2. Disabled people fear that councils simply are not resourced enough and would not be able to maintain existing support levels and flexibility. Others focused on the need for greater capacity in local authorities and the need for ring-fenced funding was highlighted by many respondents.

Typical answers included:

“I am concerned that the government is seeking to decide the future of the ILF before a decision on how social care and support will be funded in the future has been taken”

“I do not believe that Local Authorities will have the capability or capacity to take on the responsibilities of the ILF...Many social services staff do not have the necessary knowledge of disabled people with high support needs to provide an ILF ‘needs-led’ type of assessment...Local Authority’s will have little choice but to raise FACS eligibility criteria to critical needs only, thereby denying the vast majority of disabled people the support they need to maintain decent, healthy and active lives...Local Authority staff are being cut due to austerity”

“The money would need to be ringfenced for the individuals”

And one respondent who believed the 2010 closure to new applicants had affected their family stated:

“Our daughter has been placed in a Nursing/care home by [local authority social services] as the ILF was closed just as she was assessed as needing 24hour support. She is only 35 now”

Question 4: How can the Government ensure all disabled people are able to access the full range of Local Authority care and support services for which they are eligible? [NB: the original wording of this question was changed for our survey as the DWP referred to ‘Group 1 users’ rather than all disabled people. The change was to ensure people understood the question].

Strong feelings about the Government’s commitment to supporting disabled people were aired in response to this question. Many respondents focused on broader, overarching issues like the UN Convention:

“I don’t believe they are interested. Fulfill its obligations under the UNCRPD and implement the life chances report recommendations and the [Independent Living] strategy”

Others focused on the process issues and need to resolve funding, charging and other process concerns, as well as distinguish clear entitlements for

support – all of which could be addressed in broader care and support reform plans:

“By reviewing the way in which social care and support is administered and used so it is fair for all, including a fairer charging policy. The Government must ensure that the same level of funding as provided by the ILF continues for Group 1 users, as well as all other ILF users. The Government should ensure this funding is ringfenced. The Government must ensure that a needs led, not budget led assessment and review is put in place”

“provide adequate funding & ringfence it so it meets people's needs”

“A positive legal duty being imposed by the Government”

“By providing ACCURATE information and making sure that assessments and care packages are not based on the whims and opinions of individual care managers/social workers. By acknowledging the expertise of disabled people and providing better training opportunities to disabled people in the management of funding/staff management so that they can maximise their opportunities and make a more valuable contribution to society”

Others suggested monitoring changes was important (see also page 14):

“there needs to be an overviewer and someone to be accountable if things go wrong”

Many respondents highlighted the need to ensure people had access to information and advice on what services and support was available and where to get it – including through advertising support:

“Tell them how to claim it, and what is available, then support their claim, that would be a good start”

Some argued for transitional protection (see page 11) to ensure disabled people didn't lose out under any changes:

“recipients shouldn't receive less than they are getting now”

Question 5: How can DWP, the ILF and Local Authorities best continue to work with ILF users between now and 2015? How can the ILF best work with individual Local Authorities if the decision to close the ILF is taken?

Responses to this question were the most varied, but many used the space to support the status quo or repeat calls for ring-fenced funding:

“continue to leave the ILF managed by the trustees therefore ensure impartial overseeing of the fund”

“ILF money should be ringfenced within Local Authorities budgets for those who need it”

Some were angry at the limited nature of the Government consultation and this question in particular:

“This decision has not been made and I take offence that this question is being asked as if it were a sure thing”

Others gave more specific recommendations to help manage any changes, including advertising any shift in support:

“assigned case worker that can asses each case as we are all individual, no illness or disability is the same or has the same affect on each person... Each case needs individual monitoring to find the best options”

“make sure that people are aware of the changes and keep them up to date on any changes and how this will affect them”

Some made the case for working with disabled people’s organisations to co-produce any changes, implement reform and assess and monitor impact:

“ILF users and Deaf and disabled people's user led organisations should be well represented on any working party/committee which produces proposals put forward by the government on the back of the consultation”

“Government must carry out a full Equality Impact Assessment...guided by ILF users and Deaf and disabled people”

Additional questions and responses

We asked further questions to help shape our response, including on: the funding crisis in social care and support services, transitional planning, using NHS resources, regional differences in ILF use, and monitoring the impact of any changes on disabled people. The outline of responses is provided below and relates to all the formal questions posed in the Government consultation.

Funding care and support

In broader care and support plans the Government has suggested it will address care funding (overall) in the next Parliamentary term (after 2015). We believe there is a care crisis now and that the £2 billion shortfall in care funding impacts severely on disabled people's lives and ability to achieve independence and control. Disability Rights UK believes the central funding issue for all care and support services needs addressing before the ILF is closed. Of our respondents, the vast majority (94%) agreed:

Agree strongly	88.6%
Agree	5.7%
Don't know/unsure	2.9%
Disagree	1.4%
Disagree strongly	1.4%

We hope the Government will ensure funding is available for disabled people to live independently. Pressure on councils' social care budgets has already seen:

- Access to support restricted severely (with more than 80% of local authorities now only supporting disabled people with 'critical' or 'substantial' needs compared to about half of all English authorities in 2003;
- Charges to use services being levied at rates that can diminish their use – and undermine care assessments. A jump of £900 million in care charges was reported last year – taking contributions for often very

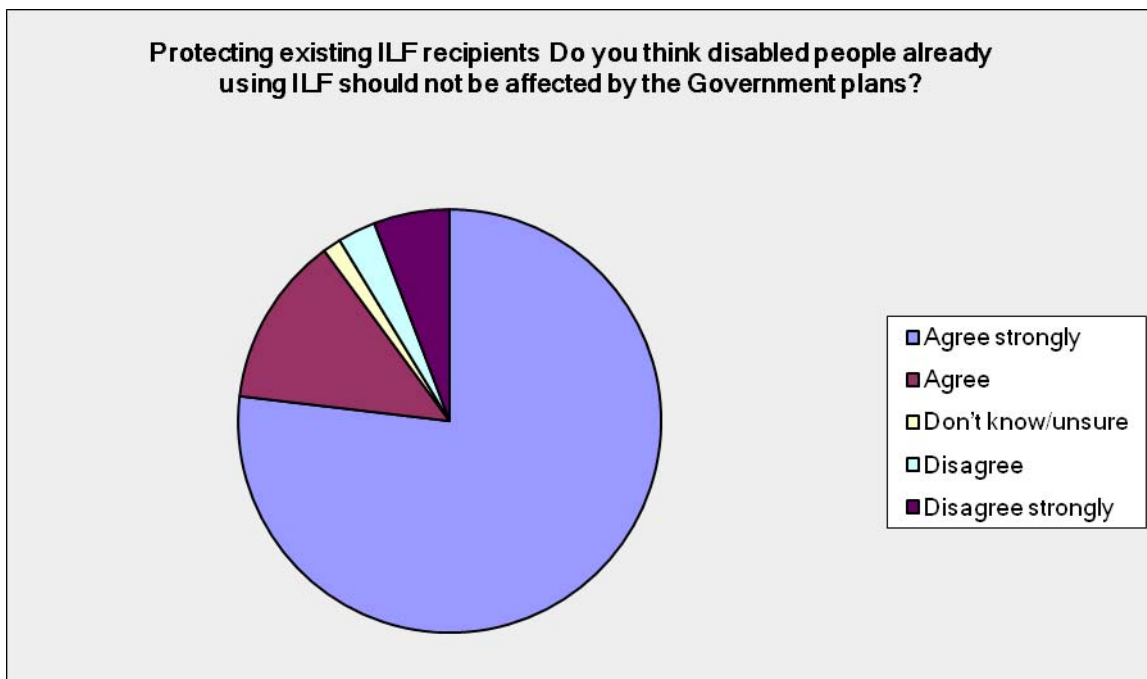
basic services to a total of £2.4 billion in the last financial year according to the NHS Information Centre;

- Councils consult on further service changes – including limited homecare support to maximum payment levels and potential automatic residential care allocation for disabled people with needs exceeding the new ‘cap’; and
- A growth in reliance on informal care providers which Age UK recently estimated costs the UK economy over £5 billion a year¹.

Transitional protection

We also asked if the existing ILF users should be provided transitional protection from any changes the Government makes to future ILF resource allocation.

- 77% of our respondents agreed strongly that existing ILF users should be afforded exemptions from the plans;
- 13% agreed with a current user protection;
- 1.4% didn’t know or were unsure;
- 2.9% disagreed with the proposal; and
- 5.8% disagreed strongly with protections for current ILF users.



¹ Largely through carers being forced to leave employment or reduce work hours as a result of informal care responsibilities. See: <http://www.ageuk.org.uk/latest-press/archive/care-in-crisis-more-than-53-billion-wiped-from-the-economy/>

Some form of protection would help ensure the Government maintains its existing commitment made in 2010 to “safeguard the position of the existing recipients of the Fund” and we would welcome assurances of how existing users will not lose out under any changes to the assessment, review, distribution of resources, monitoring and flexibility of use and how the impact of changes on this group will be scrutinised to ensure DWP meets its legal and international obligations.

Using NHS resources to help ILF users

We also asked people’s views of using some NHS funding to provide better co-ordinated help for disabled people who could otherwise lose out under Government plans. We asked if people believed greater NHS resources should be used to ensure disabled people with the highest support needs do not lose out under ILF changes. A majority of responses were in favour of this approach:

Agree strongly	54.4%
Agree	17.6%
Don’t know/unsure	22.1%
Disagree	4.4%
Disagree strongly	1.5%

We specifically asked if people believed that ‘continuing care’ funding could be more flexibly used, possibly as a form of Personal Budget or Direct Payment to help disabled people manage care and support needs:

Agree strongly	42.6%
Agree	22.1%
Don’t know/unsure	26.5%
Disagree	7.4%
Disagree strongly	1.5%

We believe the DWP consultation excluded other options by just focusing on the former Government’s proposal of passing ILF resources to local authorities. We support greater research into the needs of the disabled people using/seeking ILF support and believe the Government should explore all options before abolishing the Fund.

National/regional variations in demand/needs

The current ILF resources are not distributed proportionately by local authority areas. The Government has suggested this is an anomaly that requires redress, but it would be strange if disabled people with very high support needs were so evenly located. Inevitably, some authorities will have

more disabled people with higher support needs than others and the ILF's national position has provided an ability to top-up funding to councils that would otherwise shoulder a larger share of expenditure.

We asked if people agreed that a national top up system might be required to ensure local authorities can meet disproportionately large demand for high level care and support packages and over three-quarters of respondents agreed:

Agree strongly	68.1%
Agree	18.8%
Don't know/unsure	7.2%
Disagree	4.3%
Disagree strongly	1.4%

We believe that councils should not be penalised for having supported local disabled people better through securing ILF resources for people with the highest needs. But a geographically proportionate distribution of funding would deliver such a distortion and result in either current or potential ILF users losing out – or being protected only through councils cutting support to other local disabled care service users.

We also believe the Government proposals would exacerbate the postcode lottery in UK care services. The plans include passing ILF funding to local authorities in England. Whilst Northern Ireland, Scotland and Wales would be able to make different or similar provisions, Disability Rights UK believes this approach will increase the variables in care availability and costs. We welcome the Government's broader care and support plans² to ensure a minimum level of entitlement to care and support in England and to ensuring 'portable' support is available (through the reduction of duplicate assessments for disabled people who move from one authority to another for work or to attend university for example). We believe care and support should not be determined by where you live and that the ILF closure proposals undermine broader Government aims and risk making the 'care lottery' worse. Our respondents tended to agree:

Agree strongly	79.7%
Agree	14.5%
Don't know/unsure	1.4%
Disagree	2.9%
Disagree strongly	1.4%

² See the Draft Care and Support Bill and associated consultation online at: <http://careandsupportbill.dh.gov.uk/home/>

The Government must ensure proposals do not entrench disadvantage by either locking funding to a formula that fails to reflect areas where supporting disabled people costs more due to specific geographical issues or higher numbers of disabled people with high support needs. Any changes must be flexible enough to reflect and meet needs to ensure disabled people can participate equally as full citizens.

Monitoring any ILF changes

Disability Rights UK shares the concern of the Joint Committee on Human Rights that the Government is potentially undermining the UK's ability to meet its responsibilities under the UN Convention on the Rights of Disabled People³ - specifically to independent living.

The cumulative effect of proposed changes to the ILF, other direct payments (eg Disability Living Allowance), funding for councils to provide care services and other austerity measures. Disabled people are the hardest hit by the retraction of services and support and this must be carefully monitored to ensure the impact is mitigated.

We asked if people believed the Government should monitor the impact of this policy change, especially if the ILF closes in 2015 and 97% agreed with this recommendation:

Agree strongly	87.0%
Agree	10.1%
Don't know/unsure	1.4%
Disagree	1.4%
Disagree strongly	0.0%

We hope, if the Government presses ahead with the planned closure of the ILF, that the wishes of disabled people and ILF users particularly, are taken into account and the outcome of the changes are inspected closely to ensure no further regression of the hard-fought rights and independence disabled people have spent decades achieving.

Other issues raised by respondents

We provided some open space for respondents to tell us anything else.

Some chose to inform us of the difference ULF has made to their lives:

³ See: <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/inquiries/protecting-the-right-of-disabled-people-to-independent-living/> for further information on the JCHR work in this area.

“ILF has made my life worth living”

“Gives me real choice and control over my life and enables me to contribute and take part in society”

“The ILF has been an essential tool in keeping me able to stay reasonably healthy and able to work and participate”

Some questioned the rationale for reform and the long-term consequences:

“changes...are badly worked out, and causing stress and anxiety to the weakest in society... the current and on going changes will in the end come back to bite them...I worked for 21 years happily paid my taxes, national insurance and if wasn't struck down in the prime of my life with a serious illness I would still be working and paying my way”

“life as it is is very hard and...it is getting a hell of a lot harder”

Some supported legal action against the proposals⁴:

“I believe the Government ILF consultation is flawed as they seem to have already decided to close the ILF .I oppose the closure...The ILF offers the difference between living and merely existing. I support the legal challenge against the current 'consultation' and closure of ILF”

And some expressed the fear and anxiety generated by further changes in the essential support disabled people need:

⁴ For information on the legal action please see: <http://www.thefedonline.org.uk/component/k2/item/1776-government-could-face-court-action-over-ilf-closure.html>

“I'm crying as I fill this in because I am so scared about what will happen to me because of these devastating funding cuts... I can't face going back to being mistreated, demeaned & neglected... I'd rather be dead”

“Really very, very scared about the future and my potential loss of independence when at the mercy of a local authority under pressure to cut its own costs”

Some respondents also raised the potential economic impact of failing to take into account jobs funded through the ILF is users lost resources through any funnelling of funding through local authorities. Just 6% of adult social care expenditure funds Direct Payments and Personal Budgets, but the NHS Information Centre suggests 20% of the entire 1.8 million care workforce are Personal Assistants or direct employees of disabled people⁵. These 360,000 jobs are likely to also be funded using ILF resources – and provide associated Income Tax and National Insurance contributions to the Treasury. In the context of maximising work, reducing the deficit and Government aims to tackle welfare spending this is an important issue to consider in any changes to the ILF.

Conclusions

There is a significant amount of concern about the proposal to merge ILF resources into council grants from Government. Disabled people fear a loss of independence, control and flexibility under local authority management. We are keen to examine other research for alternatives to this approach. Many believe the changes would result in diminished support – especially in the context of councils losing other Government funding and care funding not being ring-fenced.

The Government has some way to go to reassure ILF users that proposals would enhance support and we hope DWP will act swiftly on the suggestions made in this submission – both from Disability Rights UK and from our members and others who have contributed.

We look forward to the Government's response.

Further information/speaking to individuals affected

Over 30 individuals responding to our survey are willing to speak in more detail, including publicly, about their concerns.

⁵ Figures are for England. See:

http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/Pssstaffsept11/Personal_Social_Services_Staff_of_Social_Services_Departments_revised_0712.pdf

If you would like to undertake further research and would like to involve this group of people, are interested in covering the potential closure of the ILF and its impact, or have questions about this response, Disability Rights UK, or want more information please contact Neil Coyle, Director of Policy and Campaigns at: Neil.Coyle@DisabilityRightsUK.org