

## **Joint Committee on Human Rights**

### **Inquiry into the Implementation of the Right of Disabled People to Independent Living**

#### **Submission from the Independent Living Fund**

The Independent Living Fund (ILF) welcomes the opportunity to respond to this call for evidence from the Joint Committee on Human Rights and hopes to play a positive role in assisting the Committee with this inquiry.

The ILF has provided the opportunity for our users to respond to this Inquiry by publishing the questions on our website and in our 'Living' magazine, as well as posing the questions at four recent regional meetings with users and social workers. We have received some contributions in writing that we have passed on to the Committee separately and in full.

Our submission is in two parts. The first part presents a response from the ILF with support from our advisory group of disabled people – on the future of the ILF – which the Committee has pointed up as an issue of direct interest. The second presents views from our users and partners that we have collected on the main questions posed by the Committee, and have presented without analysis or edit. We have a close relationship with our users and hold a responsibility to pass on their feedback.

## **Background**

The ILF occupies a distinct place within disability support arrangements and adult social care, bridging the support provided by local authorities and the benefits system. It is an Executive Non-Departmental Public Body of the Department for Work and Pensions, currently making cash payments through a discretionary trust with a board of trustees, to over 20,000 disabled people with complex and high support needs in all parts of the UK. Since 1988 we have pioneered direct payments and supported over 45,000 disabled people to remain leading active lives in the community as full citizens.

The ILF administers around £350 m of funding directly to its users with just over a 2% administration cost each year, enabling those with the severest impairments to lead the same lives in the community as the rest of us. The funding assists with meeting the cost of personal care and domestic assistance our users require to achieve independent living.

Our user satisfaction surveys show that 96% of our users expressed satisfaction with their award, 98% of our users are satisfied with their quality of life, 96% feel they have satisfactory choice and control over their own lives, 98% see themselves as able to live independently, and 92% (and growing) have been able to experience a wider range of activities through their awards.

In December 2010 a Written Ministerial Statement from Maria Miller, Minister for Disabled People, announced that funding for existing users would be protected for the life of this parliament and that the ILF is closed to new applicants. She also stated that following the outcome of the Dilnot Commission's work there would be consultation aimed specifically at how to develop a new model to best support the ILF client group within any new arrangements for Adult Social Care.

## Part One

### Context for the ILF

The ILF has been a significant function of Government promoting independent living for disabled people in the UK over some 22 years.

The ILF occupies a unique position advancing independent living in tandem with the non devolved DWP benefits system but on condition that there is matching funding from Local Authorities' adult social care budgets within each country of the UK. An ILF award is effectively a "personal budget" combining funding from the ILF and half of the care component of DLA, from the relevant Local Authority and the person, to support the user to manage his or her affairs in order to achieve a fully inclusive life in the community.

The key strengths of the ILF model most valued by ILF users and our partner Local Authorities, are the ring fenced nature of the funding which is safe from local cost cutting initiatives, the award is portable without the risk of a 'cliff edge' effect often experienced where a user moves between Local Authorities, and the committed service that we provide with a dedicated case holder and visiting Assessors who know the case history and are able to provide an ongoing and high quality service.

However, the number of ILF awards had always been demand led without time limit and could frequently last for a lifetime. In 2008 the previous administration took the decision to cash limit the fund. This considerably altered the operation of the funding model. Through a Written Ministerial Statement (WMS) on 13 December 2010, Maria Miller stated that the current ILF model is financially unsustainable and that the Coalition Government would consider the long-term future of the Fund. She also stated that the ILF is permanently closed to new applicants and stated that:

*"We believe there is a strong and principled case for reform (of the ILF) and for the social care support needs of all disabled people to be delivered equitably as part of Local Authorities' broader independent living strategies in line with local priorities and local accountability."*

The Trustees of the ILF understand the current position and its rationale and have worked in close collaboration with the Minister and with officials in the DWP to deliver effective support to users. We are aware that there are aspirations within DH for adult social care funding by Local Authorities to extend to meet the independent living needs of the most severely disabled people, and that the numbers of people with high support needs on HRDLA who might require special support of the kind that the ILF has provided considerably exceeds the number of people previously eligible for an ILF award under our specific eligibility criteria.

While the ILF supports consistent quality and portability across the UK, there is some unfairness in that some Local Authorities make much greater use of ILF funding than do others. And while the ILF seeks to place its funds behind outcomes related to life in the community as opposed to the basic care needs to which LAs typically confine their funding, some longer established ILF awards have blurred this distinction. ILF trustees have aimed to introduce further reforms to the Fund notably to simplify assessment and charging, and the ILF is a primary funding stream (and the only joint stream) within the Right to Control Trailblazers.

The Government has made a commitment to fund awards for existing ILF users for the length of this parliament. It also wants first to receive the conclusions of the Dilnot Commission on funding and support of care in England, following which there is to be consultation on the way forward for the ILF.

The ILF believes passionately that we in the UK have achieved a high standard of independent living support for those with the greatest needs, a benchmark that must not be lost. If a new model is needed it should be fair and equitable, that can be sustained financially, and that drives forward the independent living objectives of all Government Departments and Devolved Administrations.

Experience suggests that this model must:

- Enable full independent living;
- be co-produced with disabled people;
- have a clear focus upon a defined target group (especially to include people with learning difficulties);

- enable geographical mobility through ‘portability’ of care packages (particularly important for taking up education, training and employment opportunities);
- be sustainably managed and resourced;
- attract committed funds from local authorities;
- be effectively delivered with minimal overheads and duplication;
- be innovative, exemplary and incentivise best practice;
- provide ongoing and flexible support to users in a way which builds confidence in independent living;
- secure consistent quality and meet agreed standards; and
- combine national consistency with support for local innovation

The ILF is committed to continuing to support its existing users to enable them to achieve their aspirations for independent living and to work with Government and other stakeholders to secure the best possible outcomes for the future.

## **Part Two**

### **Views from disabled people and partner Local Authorities**

Our consultation and engagement with our users and other stakeholders (including user-led organisations and local authorities) has given us important insights into the experiences of disabled people. At 4 recent regional meetings attended by approximately 80 of our users and local authority representatives, we introduced the Joint Committee on Human Rights’ Inquiry and asked people to comment.

Comments made by our users have been passed on without edit below. We have also received contributions in writing, which we have sent on to the Joint Committee in full.

The following section summarises the responses from our discussions with our users and local authority representatives on the questions asked by the Joint Committee and these comments are representative of themes raised during the consultation meetings:

### **1 Rights need to be assured by government and require funding**

The state should act to ensure that disabled people with complex and high support needs, who face barriers to independence, are supported to overcome these barriers. People should be made aware of their rights and their rights should be consciously considered when implementing new policies and practices. Inadequate funding to achieve independent living outcomes is the main obstacle to independence.

### **2 The impact of funding changes**

The true impact of local authority budget cuts, changes to the Independent Living Fund, localisation and benefit changes may be too early to assess. However, local authority representatives have already described more limited options available to service users and the inability of many local authorities to meet anything more than basic (critical) care needs. They have also described how a lack of funding has prevented people from moving to live independently or from going to university. ILF users have expressed concerns about the chances of their awards keeping pace with their needs so that they can maintain their standard of living or retain their valued care support staff.

### **3 Participation and consultation**

People agree that consultation and involvement is vital to ensuring decisions are made that empower disabled people rather than eroding their independence. However, they want consultation that is meaningful, enables them to make a real impact on decisions and allows maximum participation. Disabled people also want to be involved in co-producing Government policy rather than just being consulted on changes to it.

### **4 Monitoring the Convention**

People felt that more should be done to make people aware of their rights and that the government should explain more clearly how their policies ensure the rights of disabled people to independent living. The ENRC, NIHRC and SHRC should work more effectively to ensure this happens and laws should be enforced with fines.

## 1 The Right To Independent Living

- Could the government do more to give disabled people the same rights as everyone else to live independently?
- What could they do to make this happen?
- Do you think the Government needs to change any laws or the way it does things?
- If so what needs to change?

*“In order to get the ‘rights’ we need the money.” - ILF user.*

Our discussions with ILF users told us that people understood that independent living was a right. They felt, however, that the Government should do more to ensure their rights were upheld.

The overriding concern of users was that systematic cuts in services and local authority budgets would ultimately erode people’s ability to live independently.

Although people generally felt that the legislation already in place was sufficient, they felt it required greater clarification and wider promotion to ensure it was enacted. People also felt that current Government plans would mean less funding, less services and less support for disabled people and that this undermined existing legislation.

Rather than changing laws, our users felt that the emphasis should be on maintaining the positive work governments have already done to improve independent living outcomes for disabled people, and on ensuring that funding remained in place to do this.

When asked how policies and practices could be improved, people made the following suggestions:

- The streamlining of services and funding streams
- The removal of bureaucracy and the amount of personal information held on disabled people
- Strengthening the law (and compliance with the law) regarding wheelchair accessibility to shops and services

- Keeping the Equality Act and re-adding the socioeconomic duty on public authorities given that disabled people are amongst the poorest in society.
- Better transport provision for disabled people, for example by incentivising taxi and coach companies to run wheelchair accessible services
- Regulating private landlords' treatment of disabled people

Regarding the latter point, local authority representatives gave anecdotal reports of the financial exploitation of disabled people with reduced capacity, now less able to access supported living placements who were unwittingly signing contracts that tied them into weekly rental for the hire of pots, pans, mops and brushes when it would be more prudent to purchase these items outright.

*“I have huge problems with transport. There are no wheelchair accessible taxis where I live...I would like the government to look at incentives for taxi and coach companies to run a wheelchair accessible service.”* – ILF user.

*“They should cut down on the amount of documented personal information that is currently required by law to be kept on disabled people with regard to their daily personal needs.”* – ILF user.

*“Despite laws to make shops wheelchair accessible there are many shops that flout the law and local authorities do little or nothing to encourage shops to provide a simple portable ramp. Perhaps the local authorities should offer a rate reduction for making premises wheelchair accessible.”* – ILF user.

## **2 The Impact of Funding on Independent Living**

- How have people been affected by changes to benefits, cuts in funding, changes in services, the way local councils decide whether you can get a service or not?
- Are these things making being independent more difficult?

As previously stated, the most commonly voiced concern of ILF users and local authority partners was that restrictions on local authority funding, the freezing of the Independent Living Fund and

closure to new applications, and increased focus of localisation would make it more difficult for disabled people to live independently. However, several commented that it was too soon to properly assess the true impact.

One of the most pressing concerns for ILF users was that the current restrictions on awards for existing users devalued their assessed funding and could eventually make their present care arrangements unsustainable. Many of our users cited their fear of losing current personal assistants or agency support if no funding is available to cover wage rises or increases in agency costs. However, the ILF intends to be able to support some increase in the cost of the current package over the next financial year, due to the level of funding that has been allocated.

*“Part of my care funding comes from ILF. ILF have stated they will not be increasing funding to existing users when hourly care rates are increased this year. Personally, I cannot afford to make up the shortfall out of my income which is only Guaranteed Pension Credit.” – ILF user.*

*“ILF cap on award has led to problems as care costs have increased. I’m worried how I am going to pay for the care I need and concerned about what will happen in ILF goes.” – ILF user.*

These problems seem to be compounded by the budgetary restrictions affecting local authorities.

As a result ILF users are already speculating about a time when their current levels of care support cannot be maintained, and on what the personal impact to them might be.

*“Interestingly enough I remember reading [that it has been decided] the ILF is ‘financially unsustainable’. If that’s the case how on earth are local authorities going to make up this shortfall through severe cutbacks they are experiencing? I would assume that existing recipients will be safeguarded when the fund closes? If not it will leave disabled people in a desperate and perilous condition if these changes are railroaded through.” – ILF user.*

“With the coming shortfall in ILF funding and no corresponding increase in my Pension Credit, I can envisage a time coming when I will not be able to receive the support I presently enjoy.” – *ILF user*.

*“The loss of this help will be catastrophic for me.”* – *ILF user*.

Local authority representatives have informed us of the effect of cutbacks in their own authorities:

- Unable to move young people into independent accommodation or support living without additional funding from ILF
- Young disabled people remaining with parents (adding increased pressure on family) or moving into residential care
- Vulnerable young people moving into private accommodation and risking exploitation by private landlords
- People planning to go to university now unable to due to lack of funding for care support
- Closure of day centres and greater reliance on voluntary placements (farms, garden centres, etc.) not necessarily the most suitable for the user
- Funding only available for critical needs

There were worries that available local authority funding will necessarily be spread more widely across social care users to ensure basic care needs are met, leaving less financial assistance available for the achievement of the independent living outcomes that the ILF seeks to support.

“Without the money people will be left with ‘life and limb support’ because local authorities will not be able to meet the demand it will create.” – *ILF user*.

*“Things have improved with Individual Budgets, but the choices are limited to being able to go out in the community and be smelly, or stay at home and be up, dressed and cleaned.”* – Local authority representative.

In response to The Written Ministerial Statement, our users told us that if ILF money were transferred to local authorities as part of the move towards a localised approach it would serve only to reinforce the “postcode lottery”. They said this would reduce the portability of care support and further restrict the ability of disabled people to move freely around the country to live, work or study.

Some users were sceptical of the “big society” initiative, claiming that emphasis on voluntary services over actual funding will diminish community inclusion, and do nothing to further the personalisation agenda or the rights of disabled people.

ILF users are also concerned about other cuts and the impact these might have, particularly in relation to housing:

*“It is now harder than ever for a disabled person to leave the parental home now that we have lost ‘my safe home’ enabling an Income Support mortgage, as landlords do not want their properties adapting to the degree that some disabled people require” – ILF User*

### **3 Participation and Consultation**

- How can the Government involve disabled people in planning services and deciding how to save money?
- How well are disabled people involved in planning and making decisions?

Article 4(3) of the Disability Rights Convention provides that State Parties shall “closely consult with and actively involve persons with disabilities...through their representative organisations” in any decisions concerning disabled peoples’ issues.

From our discussions with our users it was evident that people feel this consultation and involvement is not sufficient, or simply does not happen, as far as they are aware.

*“I don’t know how much representation from disabled service organisations the government presently takes note of, but such representation should be deeply involved.” – ILF user.*

Local authority representatives were also cynical about the actual impact of consultation in the decision-making process, echoing the concerns of our users that often the decision is a *fait accompli* and the involvement of disabled people has little or no effect on the outcome.

*“We are doing a consultation on increased charges at the moment. The question is: ‘how do you want the increased charge applied?’ – Local authority representative.*

*“We need to have a blank sheet for consultation. Actually, consultation is generally only done after decisions have been made and only small changes can be made.” – Local authority representative.*

The question of how to ensure that disabled people *are* included in the decision process and how to encourage this seems more difficult.

Some of our users were concerned that increasingly information and the means of participation were only available online. People complained that they were not able to give their views because they had no access to a computer or were not aware of the consultation taking place.

If consultation were co-produced, disabled people and their organisations would understand the issues and provide solutions and more informed decisions would be reached.

It was suggested that greater use be made of more traditional forms of media (newspapers, TV and radio) to ensure greater awareness of public consultation, rather than relying on the internet.

Other users complained about the timing of consultations (receiving short notice to provide submissions, for example) and the way they are organised, meaning that sometimes the people most affected by changes are not included in the debate.

People with learning disabilities were identified in discussions as a group most often overlooked or “left out” of the consultation

process. It was thought to be vital that the views of parents and carers were included to ensure the needs of this group were taken into account.

#### **4 Monitoring the Effective Implementation of the Convention**

Our users felt that equality laws and the Disability Rights Convention provisions should be enforced by fines against institutions, if necessary, to ensure Government compliance. It was felt that the various Equality Commissions (EHRC, SHRC and NIHRC) should take a more proactive stance in challenging the Government on the achievement of its Independent Living Strategy.

Moreover, it was felt that the Equality Commissions could do more to make people aware of their rights.

#### **Conclusion**

We hope that the commission finds this response of interest. We would be pleased to make any further evidence and information available if requested.

April 2011