

ILF response to the Call for Evidence on the Future Funding of Care and Support

28 January 2011

Dear Commissioners,

The Independent Living Fund (ILF) welcomes the opportunity to respond to this call for evidence from the Commission and hopes to be able to play a positive role in assisting the Commission to reach its conclusions.

Executive summary

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. The ILF is an Executive Non-Departmental Public Body of the Department for Work and Pensions. We currently make cash payments to over 20,000 disabled people with complex and high support needs in all parts of the UK to assist with meeting the cost of the support they require to achieve independent living. We enable those who face the greatest barriers to independent living to remain living in the community rather than in residential care and to play an active part in their community as full citizens.

The support we offer is highly regarded, but we have been committed for many years to reform of the Fund to reflect the personalisation agenda and to use our experience and expertise to further improve the way we operate alongside other funding streams for disabled people. We are fully open to proposals from the Commission and from our stakeholders that would further improve our contribution.

We therefore wish to present evidence drawn from our experience for consideration by the Commission. This can be summarised as follows:

1 Disabled people with high support needs want to lead independent lives

The state should act to ensure that disabled people with complex and high support needs, who face barriers in the way of their leading the same active lives as their non disabled colleagues in their local community, are supported to overcome these barriers.

2 The Adult Social Care and Social Security systems must work together

Evidence suggests that effective support needs to be through dedicated arrangements that integrate Adult Social Care (ASC) funding from local authorities with extra cost support from the benefit system, to provide direct payments into people's pockets so that they can employ the support they require to help them to achieve the inclusion they desire.

3 Local Authorities' focus is on basic care

Our experience suggests that local authorities are increasingly and understandably focussed upon essential basic care and not true independent living for their service users, often being confined to meeting only critical needs other than when engaged in a joint package with the ILF. Aside from the contribution of the ILF there is no means of collaborating to secure that support and provide national consistency and portability. There is in practice a clear distinction between the support for care provided by local authorities, and the support and expertise required to enable people with the highest support needs to achieve independent living.

4 So ring fenced funding and a dedicated programme are needed

Whilst resources are tight, and prioritisation is essential, there remains a need for a specific source of ring fenced funding and support arrangements, designed to enable independent living, which builds on the successful experience of the ILF and ASC working together.

Our submission contains key points from the evidence and experience we have accumulated over the last 22 years. We have attached a copy of the document we produced following our consultation with users in England about the Care Support and Independence and Right to Control, which outlines the key issues raised in those debates and highlights the ILF's desire to develop and reform our operational model to meet the needs of our users. We have also attached a copy of "Living" magazine, which contains case studies showing the effect that ILF funding has had on our users, and a copy of our user guides which explain how the ILF model operates in practice.

We have kept this initial submission brief in order not to over burden the Commissioners. However the ILF has other evidence and case studies, which it would be happy to share with the Commission. We are very much looking forward to meeting with the Commission, along with some of our users, in order to explain the needs of the ILF target group.

Submission

Comments directly relevant to the work of the ILF

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. The ILF is an Executive Non-Departmental Public Body of the Department for Work and Pensions. We currently make cash payments to over 20,000 disabled people with complex and high support needs in all parts of the UK to assist with meeting the cost of the support they require to achieve independent living.

We enable those who face the greatest barriers to independent living to remain living in the community rather than in residential care and to play an active part in their community as full citizens. We offer the accumulated expertise of our service users, our Trustees, our Advisory Group of disabled people's representatives, our management and staff and independent assessor network to the Commission.

We hope that we can help the Commission to identify the best way in which vulnerable disabled adults can be supported to live independently at home.

As well as the Trustees' long-standing experience of managing the ILF funding stream, we have built up a substantial resource of knowledge and expertise in how best to enable the exercising of choice and control to live independently, built on the lived experience of ILF users over the last 22 years.

This direct experience includes that of the strengths and shortcomings of the current funding system, and offers particular ideas on developing a reform strategy, measured against the Commission's criteria, for how disabled people with high support needs (especially those of working age) will be supported to live independently in the future.

ILF funding is targeted at those who need the greatest support to live independently, determined by: the receipt of the highest rate care component of Disability Living Allowance (DLA) and a minimum level of local authority social care funding. Users of the ILF are expected to contribute half of their DLA care component and all of any severe disability premium they receive towards the cost of their care.

The ILF has historically dealt with applications from people aged 16 – 64 and as such our interest is rooted in the arrangements for working aged disabled people.

In December 2010 a Written Ministerial Statement from Maria Miller, Minister for Disabled People, announced that the ILF is closed to new applicants and that following the outcome of this 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 ASC.

In 2009 the ILF invited responses from all of our users in England on the Care, Support and Independence, and Right to Control (RTC) consultations. We used those responses as well as responses from our regular programme of meetings with ILF users and Local Authorities across the UK and our own experience to inform this submission.

Government has recognised for over twenty years now that there is a group of severely disabled people in the UK who are at risk of being denied the opportunity to:

- participate in society as equal citizens;
- live in their own homes;
- access support to live more than a very basic existence;
- join in community activities;
- fulfil their economic potential, particularly through work; and
- exercise their human rights.

Despite attempts through the personalisation agenda for adult social care to support life in the community, with its primary focus on safeguarding and protecting ‘vulnerable people’ from being without basic levels of support, ASC supplied by Local Authorities has, in the experience of the most severely disabled people, been unable to effectively tackle their exclusion from society. Service users of the ILF have achieved better outcomes with the use of targeted funding and dedicated ongoing support from a ring-fenced budget. We have long acknowledged the need to reform the current system and believe that a new model of support is now required, but our firm view is that this needs to look beyond the mainstream funding of social care from local authorities.

Experience suggests that this model must:

- **enable 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**

Wider comments on the issues raised by the Commission

Specific comments on some of the issues raised within the “call for evidence” document are provided below.

National Consistency - locally responsive, national access

The ILF is a UK wide resource and the eligibility requirements and assessment process are the same wherever in the UK a person lives. Our system allows for a unique portability of assessments and awards across the UK. We have a wealth of experience in delivering a service that is accessed nationally, but which is also locally responsive with face-to-face meetings between users, locally based self-employed assessors and local authorities, working together in close partnership.

Through our consultation in 2009 we are aware that the inequalities in levels of provision of social care across the UK are a significant issue for disabled people:

“There should be equality in provision nationally with no difference when you applied, what age you are, where you live or how vocal the individual”

However people want to receive services that are appropriate for the local community:

“Minority needs and the vital services associated with them may need to be protected”

And to have face-to-face contact with local people who can offer advice and support to enable them to make the best use of their funding. ILF Users regularly report that the ILF assessment process with an assessor, who has local knowledge but is independent of the local authority, is highly valuable to them in producing personal support plans to secure the outcomes they desire.

The ILF has proved to be a flexible operational model, which is able to provide national consistency whilst working in partnership with differing local authority policies and the Devolved Administrations. This has enabled us to make national policy changes quickly and equitably, whilst remaining a resource that is ultimately locally delivered.

Standard setting and maintenance within the system

We agree with the Commission's view that there should be a focus on prevention within any care and support funding system. However as more local authorities lack the resources to meet anything other than critical needs it is hard to see how this can be translated into reality without more resources being made available. Social workers have told us that whilst ILF support is very welcome for those with the greatest need and the highest cost care packages, often those who really miss out are people with moderate needs who cannot access local authority funding and subsequently are not eligible to receive ILF support.

An inability to meet a person's moderate needs can lead to them needing a larger package of support down the line. We believe that comprehensive packages of support, which enable people to access a variety of social and leisure opportunities, can avert problems later in life, through maintaining good mental health and avoiding physical deterioration wherever possible.

Service standards and quality services that allow people to exercise choice was a big concern for users who responded to our consultation. For example:

“Choice and control are meaningless so long as there is not enough high quality provision from which to choose”

“In my experience, there are a limited number of service providers with the professional expertise. Most seem to employ staff on minimum wage and struggle with finding staff”

Direct payments, which the ILF pioneered, are seen as the preferred method of enabling users of social care to exercise choice and control over the services they receive. All ILF users receive a cash sum paid as a direct payment from the ILF to spend on care, and this has provided a positive encouragement to local authorities to offer direct payments, and to be increasingly flexible as to how these can be used. Despite this we estimate that only forty-one percent (41%) of ILF users are in receipt of a direct payment from their local authority and this rate varies significantly in different areas of the UK. This suggests that there is a long way to go before all social service users are able to exercise full choice and control over their care arrangements.

However, we know that when direct payments work well this can be empowering for the service user and provide better outcomes. For example, one user told us:

“My carers are happy and know that I am in control. Long may this remain so”

The ILF attempts to drive up standards from local authorities by expecting minimum input in cash terms and setting standards (for example by insisting on one to one support in supported living) before becoming involved in funding a package of support. We believe that there is a strong case for maintaining a national element and source of pressure for consistency on the adult social care system, and to set and oversee standards for independent living across the UK.

Effective partnership between Government departments with an interest in adult social care and social security

The ILF recognises the strengths in the continuation of separate funding streams with their expert knowledge and the power to drive up each other's performance, but would like to see duplicity removed from the system and a drive towards streamlined and collaborative working between funding streams, including methods for calculating user contributions.

Through our consultations, our users have repeatedly raised the issue of having to undertake multiple assessments of need in order to access the range of services they require. There was a call for:

“A common criterion for access to services with a single point of application, assessment and monitoring.”

This was seen as necessary both to simplify the current system and to reduce the levels of bureaucracy currently experienced by users. However, users also consistently rate the ILF assessment process as good and tell us that it is often more holistic than that of the local authority. Our experience suggests that whilst streamlining of the system is important, where multiple assessments add value they should be maintained.

There are many overlaps within the current system. The ILF approach helps to address this by ensuring that half a person’s DLA is contributed towards the cost of their care. However, multiple funding streams, each with its own set of rules and criteria, are often brought together to form a complex and sometimes overly burdensome care package. For example seven and a half percent (7.5%) of ILF users also receive funding from Supporting People and eleven point six percent (11.6%) receive NHS funding. Others receive Disabled Facilities Grants and Access to Work funding; in addition to the funding they receive from the ILF and ASC.

There are undoubtedly benefits to having different funding streams each with a defined purpose and ring fenced funding, and indeed discrete Government programmes with funding for specific outcomes will always exist. However there tends to be unnecessary overlap in eligibility criteria and a lack of shared monitoring and expenditure requirements, which can make things at best confusing, and at worst impossible for users to manage. Additionally, administering various funding streams with overlapping purposes can result in money being lost from front line service provision.

The same problems exist with multiple assessments in relation to charging as do with assessment of need. Users of social care services often face multiple charges and funding streams often have different criteria on which they assess a person's ability to contribute. A lack of data sharing between agencies results in people having to give the same information more than once.

The RTC Trailblazers are currently attempting to overcome some of these barriers. The ILF is one of the funding streams participating in the Trailblazers and our experience so far indicates that whilst there are a number of challenges to overcome, there is a genuine willingness to improve the system. Our observations to date include:

- Bringing together multiple funding streams with different purposes and cultures is inevitably challenging and this is made more difficult by the current financial climate.
- Sharing information effectively between multiple parties in multiple locations is always liable to be problematic.
- Expertise and understanding of processes and rules is limited to within funding streams and not easily transferable because of complexities of rules and policies. However working together has improved understanding.
- By exploring different models the Right to Control does present an opportunity to overcome some barriers particularly by focusing provision on the outcomes that the individual wishes to achieve.

Meeting the needs of disabled people with complex and high support needs

ILF understands that the Commission is looking at the wider picture. Part of the wider picture consists of particular groups for whom special provision is required and whose special needs must not be overlooked. ILF users represent one such Group. We would like to stress the importance of, whatever broader conclusions the Commission reaches, ensuring that proper provision for groups such as people with complex and high support needs is integrated as part of a comprehensive and coherent strategy, and not bolted on later as an afterthought.

All ILF users require significant levels of support to live in the community, with the overwhelming majority needing a “safety net” in order to ensure they receive the support they need to achieve independent living.

Indeed all applicants since April 2009 required an income not in excess of twenty-five percent (25%) above IS levels (earned income aside), for their ILF application to be successful. Less than one percent (1%) of ILF users are in work for more than 16 hours a week – a figure that highlights the limited opportunity that severely disabled people have to accumulate assets. Furthermore those with life long disabilities are not likely to be able to purchase insurance against their future care needs.

We have recently analysed the characteristics of our user base. Whilst emerging statistics should be taken with some caution, some thirty three percent (33%) of ILF users have a severe learning disability as their main impairment, and around sixty percent (60%) of the ILF user group have some degree of learning disability; consistent with the commission’s findings that sixty percent (60%) of Adult Social Care funding spent is on this group. Of these almost one third are residing in supported living settings, almost always with 24-hour support. Many of these people have previously lived in residential care or long stay hospitals and these new arrangements represent a great leap forward in provision and independent living outcomes for this group. Local authority representatives have told us that supported living placements for this group are becoming harder to finance since ILF stopped accepting applications with one social worker saying:

“Perhaps the availability of ILF has led some of us in local authorities to have a distorted perception of the possibility of large supported living packages”

We would stress that as part of any reform it is essential that advances in this area continue to be made and people are not expected to “make do” with packages that do not support full independence.

We also assert that the concept of “fairness” within any system needs to be measured in terms of outcomes rather than input if true equality for all disabled people is to be achieved. In order to enable full independent living and to protect human rights, there are some groups of people who will require more expensive packages to overcome the barriers they face. It should be recognised that the high cost of support needed for some individuals should not debar them from achieving independent living on an equal footing.

It is also important that any system designed to provide a “safety net” does not distinguish between services given to those reliant on state funding and the services that can be purchased by those with their own assets. A two-tier system must be avoided in any reform.

With regard to the funding of any future care and support arrangements, sixty-eight percent (68%) of people who responded to our consultation on the Care Support and Independence green paper preferred the comprehensive option (where everyone gets care free when they need it in return for paying into a state insurance scheme if they can afford it, whether or not they need care).

“The ‘comprehensive’ option every time. I’d be prepared to pay higher taxes to ensure that I, and each person who requires care, get what we need”

Twenty percent (20%) of respondents preferred the partnership option with only four percent (4%) expressing a preference for the insurance option (8% expressed no preference).

It was also felt by respondents to the consultation that there is a strong case for having two different funding systems; one for disabled adults of working age who are likely to require life long support to live independently and one for those needing care when older.

“What the government needs to do is look separately at the needs of young people who have long-term care needs”

The ILF firmly supports the view that the funding arrangements for working-age adults should be underpinned by a right to independent living, regardless of the individual's ability to contribute financially:

“We have a whole life to lead with the restrictions of what you will and won't fund us to do”

With regard to the Commission's request for evidence about **value for money within different parts of the care system** the ILF has a lot of expertise to offer, as we have been able to provide awards to users with an administration cost of only two and a half percent (2.5%) of our total budget. This includes money paid to users to purchase support with managing their funding. This can be seen as one of the key advantages of a nationally delivered system where administration is centralised enabling a cost efficient and adaptable method of delivery within which national policy changes can be implemented quickly. This type of model is ideally suited to working in partnership with locally based third-sector and user led organisations, helping to ensure that they are sufficiently financed and skilled to support users with making best use of their allocated funding.

Support for carers

Despite often having relatively large packages of support, twenty-three percent (23%) of ILF users have someone in receipt of Carer's Allowance caring for them. This suggests that there are significant amounts of unpaid care being given on top of the care that is being paid for by public funds. It also suggests that even with a large support package there is still a level of unmet need and a willingness from relatives and friends to meet this need, which we believe must be nurtured and maintained.

Many relatives of ILF users are concerned that Carer's Allowance ceases at age 65 (an issue which is regularly raised at user meetings). The Commission may wish to address how this fits with a desire to value carers. There are a large number of elderly carers caring for their adult children. For example the Learning Disability Alliance Scotland estimates that there are 7,000 people aged over 65 caring for adults with learning disabilities in Scotland alone, and this reflects our experience as well.

We believe that the Commission should also consider the impact that properly funded packages of support have on the wider family situation. We are frequently told that without the additional support the ILF provides, parents would be unable to keep their sons or daughters at home and may have to consider residential care, or that a main carer would be unable to work. At a recent user meeting in Northern Ireland, we were told that any changes made to the ILF need to consider the effect on the users family, as removal of funding could lead to less independence for the user and affect family members ability to work.

A properly funded care and support system is then not only about the independence of the user but also the opportunity for those close to the user to continue to play a full part in, and contribute to society.

Conclusion

We hope that the commission finds this response of interest. We would be pleased to make any further evidence and information available to the Commission and look forward to the opportunity to discuss our evidence if a meeting can be arranged.