

## ***Independent Living Fund Response to “Caring for our Future”***

### **Introduction**

The Independent Living Fund (ILF) welcomes the opportunity to respond to this request from the Department of Health for comments. This submission provides the views of the ILF trustees and senior management, and does not seek to convey the views of our parent department, the Department of Work and Pensions.

Our comments are primarily directed towards the two subject areas of personalisation and integration, and relate to the client group and purpose that the ILF supports namely **for severely disabled people with high support needs in receipt of Higher Rate Disability Living Allowance and Local Authority funding and aged between 16 and 65 to use their awards to live full active lives in their local communities.**

This response is in three parts

- Part One - Our position on the future of the ILF within the care system
- Part Two - The experience of operating a separate fund
- Part Three - How ILF experience might have benefits more widely for ASC
- Part Four - Some comments on personalisation and integration

**The future of the ILF, which utilises some £350m of Government money each year and supports around 20,000 disabled people, is under detailed consideration by the DWP and has been identified by the DWP Minister as an issue for resolution in the context of the wider reform of the care and support system.**

Our evidence takes as its basis the following words from the consultation leaflet issued by the Department of Health, which provide a rationale for much of what the ILF seeks to achieve:

*“We want everyone to have the help they need to live independent, active and healthy lives and to be part of the community. Care and support is something that affects us all – we all know someone, a family member or friend, who needs additional care or support to lead full and active lives. Today, some people can get help from the state to pay for their care and support costs. Disability benefits provide a basic level of support to everyone who has a care and support need, regardless of their income or wealth. The state provides additional support through the social care system for people on low incomes who cannot afford to pay for themselves if their local council decides that they need help.”*

The ILF is currently the subject of a proposal to adjust the positioning of the dividing line between the two systems. DWP has a preference for transferring the users of the ILF to full funding by Local Authorities and sees the current DWP contribution to the joint ILF award becoming part of the DH responsibility for adult social care. It intends that there will be consultation as part of the Government’s handling of and response to this current inquiry into the funding of care and support.

The trustees and senior management of the ILF are fully committed to assisting the Department to implement this aim, with the priority being to provide appropriate protection for ILF users, who have built their lives around the current levels of support they receive. However there are significant potential challenges barriers and costs for the DH and the devolved administrations, and as these would appear to be highly relevant to wider decisions about the way the two systems work together, this submission puts forward the considered views of the ILF Trustees and hopes that they will be carefully examined by Departments before final decisions are made.

## **Part One - Our position on the future of the ILF within the care system**

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 around 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, encouraged by the 2007 independent review of the ILF, to reform of the Fund to reflect the personalisation agenda and to use our experience and expertise to further improve the way we integrate with and operate alongside other funding streams for disabled people. Such reforms have been partial, largely because of uncertainties in Government about the best direction for the fund. Government sets our powers and funding and we remain fully open to proposals from Government that would further improve our contribution, and have many positive suggestions to offer.

The future of the ILF is currently the subject of consideration by the DWP, whose preferred option has been that our users transfer to the full control of Local Authorities. However delivering a solution that provides suitable protection may be hard to establish and the Minister has stated a wish to make final decisions on the ILF in the light of the government's response to the proposals of the Dilnot Commission, and hence the outcome of "Caring for our Future" is very relevant to the next stage in the life of the ILF.

We therefore wish to present evidence drawn from our experience for consideration by the Department. Our overall view as presented to the Dilnot Commission 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**

Whilst partnership working can always be improved, evidence suggests that the ILF model of providing support through dedicated arrangements with high levels of individual service that integrate Adult Social Care (ASC) funding from local authorities (for clients identified locally in line with local strategies) with extra cost support from the benefit system, can provide direct payments into people's pockets at local level 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 whilst many Local Authorities have a clear commitment to independent living, local authorities in general are increasingly and understandably focussed upon essential basic care and not upon full 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 to provide national consistency and portability. There is in practice a growing distinction between the support for basic care provided by local authorities, and the extra support and expertise required to enable those much fewer people with the very highest support needs to achieve independent living.

**4 So for this particular group of disabled people ring fenced funding, external leverage and a dedicated programme are needed**

Such a ring fence is impossible to operate within ASC so, whilst resources are tight, and prioritisation (possibly in favour of young people in transition) is essential, there remains an

argument for a specific source of dedicated funding and support arrangements, designed to enable independent living, which places obligations upon the amount and purpose of some Local Authority funding, and which builds on the successful experience of the ILF and ASC working together in an integrated model.

## **Part Two - The experience of operating a separate fund**

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 around 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 to the Department of Health 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. We hope that we can help 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 23 years, and upon advice and experience from organisations of disabled people across the UK.

This direct experience includes that of the strengths and shortcomings of the current funding system, and offers particular ideas on developing a reform strategy 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.

Government has recognised for nearly 24 years now that there is a group of severely disabled people in the UK who require discrete arrangements to meet their care needs because they 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 specialised support from a ring-fenced budget.

**We have long acknowledged the need to further develop 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 quality independent living;**
- **be co-produced with disabled people;**

- **have a clear focus upon a defined target group**
- **consider the specific needs of 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**
- **provide dedicated levels of individual service to build confidence**

What can we afford?.....

The ILF has been a huge success story for the UK in demonstrating how some of the most severely disabled people can be supported to live the same lives in the community as everyone else. But this excellence is costly and understandably in times of economic difficulty hard questions are asked about how many disabled people society can enable to receive equality of opportunity. This group of UK citizens needs this support in some measure, however constrained by resources, and however needs must be prioritised. If the ILF were to close altogether, the features set out above need to be replicated as far as possible within the replacement arrangements established by the Department of Health and the Devolved Administrations for the client group. If the decision is for the ILF to continue we would wish to see considered reform that equally well preserved these features

**We believe that the policy objective should be to establish the right affordable and sustainable arrangements for the support of the whole cohort of severely disabled people, and that – in order to avoid inequity or oppressive workloads in Local Authorities - any change to the future support for existing users of the ILF should only be determined once these arrangements are in place.**

## **Part Three - How ILF experience might have benefits more widely for ASC**

### **National Consistency - locally responsive, national access, individual service**

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, and flexible to local approaches.

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”*

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

However people want to receive services that are appropriate for the local community 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 an effective and flexible operational model that is able to provide a degree of national consistency whilst working in partnership with differing local authority policies and with the Devolved Administrations. This has enabled us to make national policy changes quickly and equitably, whilst remaining a resource that is locally delivered.

## Standard setting and maintenance within the system

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, that 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 is a big concern for users who have responded to our consultations. 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”*

The ILF pioneered the use of Direct Payments for disabled people from all the different impairment groups. Direct payments have become, not least through the leverage of the ILF upon Local Authority funding and practice, 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 some 60% of ILF users are still not in receipt of a direct payment from their local authority and this rate varies significantly in different areas of the UK and for different impairment groups. 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, and that this will continue to be a brake on the roll out of personal budgets.

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 ASC 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 duplication removed from the system and a drive towards streamlined and collaborative working between funding streams, including methods for calculating user contributions.

Our users do raise 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 is seen as desirable both to simplify the current system and to reduce the levels of bureaucracy currently experienced by users. However, users 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 suggest 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 7.5% of ILF users also receive funding from Supporting People and 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 Right to Control trailblazers***

The Right to Control (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 RTC does present an opportunity to overcome some barriers particularly by focusing provision on the outcomes that the individual wishes to achieve.

We believe that the trailblazers are pointing the way towards more integrated delivery arrangements across all the funding streams involved that provide a much more user friendly service to the customer without losing the policy intention of the separate funding streams.

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

Part of the wider picture consists of particular groups for whom special provision is required and whose needs must not be overlooked. ILF users represent one such Group. We would like to stress the importance of, whatever broader conclusions the Government 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 25% above IS levels (earned income aside), for their ILF application to be successful. Less than 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 33% of ILF users have a severe learning disability as their main impairment, and around 60% of the ILF user group have some degree of learning disability. 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, and that the removal of the ILF as exemplary provider of new large support packages is helping to reinforce a local view that Councils can now ignore this aspect of equality for disabled people with their non disabled colleagues

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. There should be no levelling down. The Government’s responsibilities for implementation of the UN Convention on Human Rights may be relevant here, as Departments determine how to maintain or replace the contribution of the ILF.

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.

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”*

### **Value for money**

The ILF has plenty of expertise to offer, as we have been able to provide awards to users with an administration cost of around 2% 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 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 Department 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 Department 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.

## **Part Four - Some comments on personalisation and integration**

### **Comments on the Personalisation Questions**

*a. How could we change cultures, attitudes and behaviour among the social care workforce to ensure the benefits of personal budgets, including direct payments, are made available to everyone in receipt of community based social care? Are there particular client groups missing out on opportunities at the moment?*

The work of TLAP is important and needs to be strongly promoted especially the performance standards. Learning disabled people appear to find it harder to access DPs but in the experience of the ILF can effectively manage these. Currently the previous ILF target group is unable to access the ILF and the extent to which LAs are making up the difference is very uncertain.

*b. What support or information do people need to become informed users and consumers of care, including brokerage services? How could people be helped to choose the service they want, which meets their needs and is safe too? How could better information be made available for people supported by public funds as well as those funding their own care?*

The many organisations of disabled people are very well placed to connect with disabled people and promote self directed support, and to help those with needs to explore options. But many of these organisations remain weak, and DH and DWP programmes of support to them, especially for networking with local partners and other DPOs could be an excellent investment

*c. How could the principles of greater personalisation be applied to people in residential care? Should this include, as the Law Commission recommends, direct payments being extended to people (supported by the state) living in residential accommodation? What are the opportunities, challenges and risks around this?*

The ILF does fund people living in supported accommodation but requires that they are absolutely free to select where they live and who can enter their home. Such principles would be harder to introduce to residential care homes, and there is a danger of tokenism. Might be better to address choice and quality issues directly

*d. How could better progress be made in achieving a truly personalised approach that places outcomes that matter to people, their families and carers at its heart? What are the barriers? Who has responsibility and what needs to change, including on the legislative front?*

The comments on integration below are relevant here. There will always be separate funding streams with their discrete aims and conditions. What matters is how they are brigaded together and reinforce each other, with integrated assessment and a common vision that puts personal outcomes to the fore.

### **Comments on the Integration Questions**

*a. What does 'good' look like? Where are there good practice-based examples of integrated services that support and enable better outcomes?*

The ILF experience is that it is possible for two funding streams, where taxpayers money is assigned through different

government departments to two different programmes for legitimately different reasons, to be delivered through partnership working to achieve more than the sum of the separate parts and a coherent service to the recipient. The Individual Budget pilots and more recently the Right to Control Trailblazers are identifying ways of doing this even more effectively. The ILF has plenty of experience in setting leverage criteria for its funding which require minimum standards of quantity and quality of activity from Local Authorities (e.g. threshold sums that must be in place, attendance at client review visits, basic care needs met) which could be replicated for other programmes where national standards or ring fencing within the ASC system would otherwise be necessary

*b. Where should services be better integrated around patients, service users and carers – both within the NHS, and between the NHS and local government services, in particular social care (for example, better management of long term conditions, better care of older people, more effective handover of a person’s care from one part of the system to another, etc)?*

A major contribution of the ILF is to make it easy for a care recipient to move to a different Local Authority area and retain their funding and care package. This could be replicated for other groups.

## **Conclusion**

We would be pleased to make any further evidence and information available to the Department and look forward to the opportunity to discuss our evidence if a meeting can be arranged.

Independent Living Fund  
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