

living

for independent people spring 11

The Joint Committee on Human Rights call for evidence

04

What is the Right to Control and how it might affect you

06 - 07

Meet the ILF user who is achieving his ambition to improve services

10 - 11

Listening to you

Making sure your views on social care get heard

ilf
independent
living fund

Making choice real for disabled people



welcome to living magazine

a space to air views and share stories

Contents

ILF update	03
ask the expert	04
the big feature	06
policy update	07
independent thinking	08
my life	10
in your area	12

Got something to say?

Contact living at
Independent Living Fund
Equinox House
Island Business Quarter
City Link
Nottingham
NG2 4LA

Tel: 0845 601 8815
or 0115 945 0700

Textphone: 0845 601 8816

Fax: 0115 945 0942

Email: living@ilf.org.uk

To subscribe to future editions of living please tell us your email address.



When you have finished with this magazine please recycle it.

hello!

Help us make living a success and subscribe for future editions by email

Subscribe to living

Some of you may remember our special launch edition of living landing on your doormat back in October 2009.



We want to send you more regular editions of living but we need your help to make this a success. So, if you want to stay close to all things related to the ILF, please let us have your email address. You can email your address to living@ilf.org.uk.

Why not also take the opportunity to give us your views and tell us your stories. As you will see from reading through this edition we are well practised at listening to what you have to say and acting on it.

Supporting you

We wrote to you in December to explain that the Minister for Disabled People had announced that the Government would protect our budget to continue to support you until 2015.

Over this period we will further develop our service and ensure that we continue to provide you with the highest levels of service.

Of course, we will continue to keep you up to date with our activities and any further developments or consultations, all the time making sure your voice is heard.

Next time – in your own words

We're good at listening and we want to hear what you have to say. In future issues of living, this page will be dedicated to letters we receive from ILF users. So if you've got something to say, drop us a line to air your views or share your stories. Just write to us, give us a call or email living@ilf.org.uk

ILF update

read the latest news from the ILF

making changes

We have made some changes to how you access our information and the time you have to contact us if you aren't happy with our decisions

Our information

You may have noticed some changes to the websites you now need to visit to find information about the ILF.

Last October, as part of an on-going initiative to converge Government information on to a small number of customer centred websites, our website merged with Directgov and the DWP website.

The new content on our Directgov pages provides all the information you need but in a different format, and structured to reflect the journeys you go through. You can see this at <http://bit.ly/gFdOJS>

Our corporate information, such as policy documents, corporate publications like our business plan, and information about our business and how it works, is on the DWP website www.dwp.gov.uk/ilf

You may notice that our user guide booklets are no longer available to download from either website.

If you want a set of our booklets all you need to do is email or give us a call and we can send them straight to you.

Listening to you

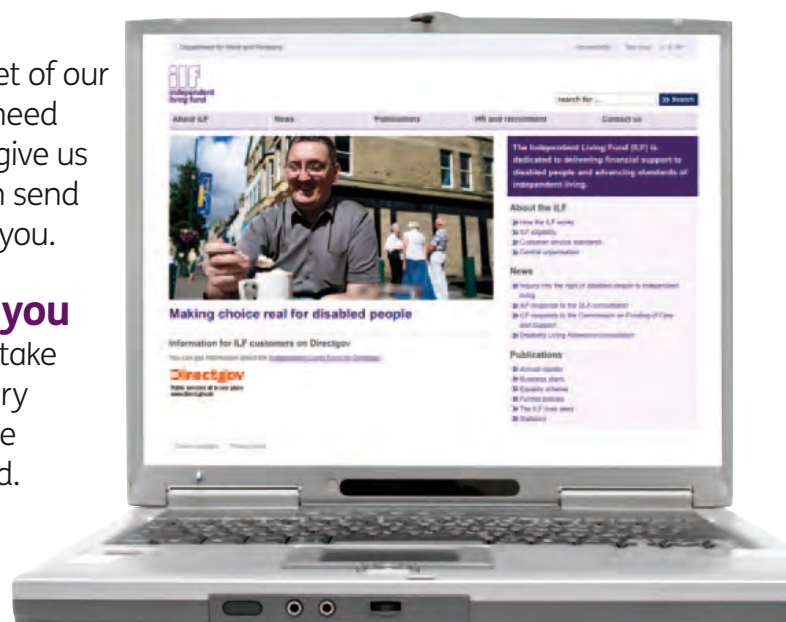
As you know we take your feedback very seriously, both the good and the bad.

We try not to make mistakes, but they do sometimes happen. If the mistake is more serious and you're not happy after we have responded, you can make an official complaint.

If you want to make an official complaint, you need to write to one of our Complaints and Decision Review Managers within three months of our response to you.

We will then try and reply to you within 15 working days.

If we think it will take longer than this to give you a full reply, we will write and let you know.



For more information on anything to do with complaints and decision reviews please contact the Complaints and Decision Review team on 0115 945 0700 or email complaints.review@ilf.org.uk

If you have any questions about the information we provide, please contact the Communications team on 0115 945 0700 or 0845 601 8815, or email communications@ilf.org.uk

ask the expert

helping you get the most from the ILF

We explain all about an important inquiry into independent living for disabled people and how you can get involved

“What’s the inquiry about?”

The Joint Committee on Human Rights inquiry looks into the implementation of the right to independent living for disabled people. This right is guaranteed by the UN Convention on the Rights of Persons with Disabilities. The Committee has invited interested people and groups to send them written evidence on this issue by Friday 29 April 2011

“Who should respond to the inquiry?”

Well, one of the questions the Committee asks is how recent changes to the Independent Living Fund could affect the right to independent living.

So, we think it is important that you and other disabled people and their families respond to the inquiry.

The Committee wants to hear how you think the Government and public bodies can implement the right in practice.

“Who should I respond to?”

You can send your evidence directly to the Committee, or send it to us and we will forward



Tell the Committee your views on these developments

- Changes to the Independent Living Fund
- The decision announced in the Comprehensive Spending Review to remove the mobility component of Disability Living Allowance for all people living in residential care
- The “Big Society”
- Restrictions on local authority funding, social care budgets and benefits reassessments
- Increased focus on localisation and its potential impact on care provision and, specifically, on portability of care and mobility for disabled people

it on to the Committee for you. If you send your evidence to us we use it to inform the ILF submission to the Committee.

Please mark any correspondence with ‘independent living’.

For more detail about the inquiry and how to respond visit <http://bit.ly/ggEh5Q>

Send your evidence to:

Independent Living Fund
Equinox House, Island
Business Quarter, City Link,
Nottingham
NG2 4LA
Tel: 0845 601 8815 or
0115 945 0700
Textphone: 0845 601 8816
Fax: 0115 945 0942
Email: living@ilf.org.uk

policy update

keeping you in the picture

information for employers

The ILF provides specific financial support to users who directly employ their own Personal Assistants (PAs)

We can't currently help meet increases in your care costs and needs. But we are still able to help you with some of the costs you face if you employ your own PAs.

Payroll support

If you find that issues such as tax and national insurance are too complicated for you to manage, you can pay a company to deal with this for you. We can consider covering these costs for you.

Task training

You might take on a new PA and need an existing PA to train them in tasks they will need to do. If this happens we can consider paying for the extra hours required whilst the PA is being trained.

Criminal Records Bureau checks

The ILF can consider helping towards the cost of these.

Health and safety training

After you have carried out a risk assessment for your PA, we can consider paying for any health and safety training that has been identified.

Employers' liability insurance

As an employer you normally need to have Employers' liability insurance and we can consider paying for this.

National insurance

We will include an amount for employer's national insurance contributions within almost every offer. We can include a standard amount or you can let us know how much you need.

Statutory sick pay (SSP)

If your PA is sick and needs to be paid SSP, we can consider paying any difference between the SSP amount and the amount that can be recovered from Her Majesty's Revenue and Customs.



Norma Bannister, ILF user, and one of her PAs

Statutory holiday

We will include an amount for PAs holiday pay in every offer.

Notice period payments or loss of earnings

If you find you have to end the employment of a PA, you may need to pay them whilst they are working their notice or compensate them for their loss of earnings. We may be able to help towards some of these costs, although we may not be able to cover every cost you incur.

Being an employer is not always easy and involves quite demanding responsibilities. We know that many of you greatly value the independence and continuity you gain by directly employing trusted people. We are committed to do all we can to support you in this role.

For more information about being an employer, visit Directgov <http://bit.ly/bmsPno>

the big feature

our part in the Right to Control

you are in control

The Right to Control is a new right for disabled people that gives them greater control over the support that they need

The Right to Control is about disabled people making their own decisions about the support that they need, instead of other people making decisions for them. It will

test new ways of working between December 2010 and December 2012. In order to allow this there have been changes to legislation and we have also amended our Trust Deed to allow more flexibility.

The Right to Control has been co-produced with disabled people and we have ensured that your views and opinions are heard. It is being piloted in 12 authorities in England called Trailblazers.

Who is eligible?

If you are an ILF user and live in any of the following 'Trailblazer' areas you will have the Right to Control.

*London Borough of Barnet
Essex County Council
Leicester City
London Borough of Newham
Reigate and Banstead
Epsom and Ewell
Sheffield
Barnsley
Bury
Oldham
Manchester City
Stockport
Trafford*

What difference will it make?

If you live in a 'Trailblazer' area you will have more control over the support you receive. You can agree to use the support you receive from your local authority towards meeting your needs in ways that work best for you.

ILF consultation

In 2009 we ran a consultation with 15,000 of our users. Over 600 of them returned our questionnaire, telling us about the issues that were important to them. We also ran eight events around the country, which 127 users and their carers attended to give us their opinion.

We reported all of the feedback we received to the Office for Disability Issues, who oversee the running of the Right to Control.

Many of you told us you want a simpler system in which different organisations work more closely together and share information more effectively.

We are working closely with the different organisations involved in the Right to Control to achieve this.



We will also check to see if you may be eligible for any additional support towards your housing needs or if you are interested in any support towards work.

What will happen next?

If you live in a Trailblazer area, our independent assessors will discuss what this could mean for you at your next review. You will be able to decide if you want to change the way that you receive your support.

Further information

If your next review is not for some time and you wish to know more about the Right to Control please contact us for more information. We can also put you in touch with the user led organisation that has helped to develop the Right to Control in your area. They can also work with you and explain how Right to Control may help you.

Regional contacts

For more information about the Right to Control in your area contact your regional team.

EastMidlands@ilf.org.uk

London@ilf.org.uk

NorthWest@ilf.org.uk

SouthEast@ilf.org.uk

YorkshireAndTheHumber@ilf.org.uk

Support services working with the ILF to deliver the Right to Control

Access to work

Can pay towards a support worker or the equipment you need at work as well as transport to and from work.

Work choice

Supports disabled people to find work, providing help with personal skills and work-related advice to get you into supported or un-supported work as well as to start work and stay in your job

Supporting people

Provides help to people to stay in their own home including:

- Setting up and maintaining a home or tenancy
- Developing domestic/life skills
- Managing finance and benefit claims
- Establishing social contacts and activities
- Accessing training and employment
- Advice and support on home improvement/repair work

Adult social care

Provides assistance to live in the community including care services and direct payments delivered by your local authority

Disabled facilities grant

These are given so you can adapt your home to enable you to continue to live there

independent thinking

discussing the issues that matter

presenting your views

How we are helping you “have your say” by responding to Government consultations that affect you

At this time of change for the ILF and the wider social care system, we have continued to meet with you, take on board your views, and feed your views back to government.

Call for evidence on care and support in England

In February, we responded to the call for evidence from the Commission on Funding of Care and Support in England. We said that independent living could only be achieved through dedicated support for people with high support needs.

We believe that specific ring fenced funding for independent living with effective client support is necessary to enable active and inclusive lifestyles for disabled people. This is regardless of who provides it.

Reform of Disability Living Allowance

The Government’s consultation seeking views on proposals to replace Disability Living Allowance (DLA) with a new benefit – the Personal Independence Payment (PIP) closed on 18 February.

The Personal Independence Payment would be a non-means tested benefit to cover the extra costs a disabled person might face.



We asked our users at a series of local consultation events, how the proposed changes to DLA might affect them, and how best the reform of DLA might be addressed. We then formulated a response to DWP based on your comments. We explained that ILF and DLA



“It’s very encouraging that the ILF is genuinely listening to our concerns”

ILF user



A vision for the future

“Effective support comes from combining funding from local authorities with extra support from the benefit system focused on independent living.

It puts money directly under the control of disabled people to buy and organise the support they need to live at home and be active citizens like anyone else. Even in difficult economic times, everyone should have the right to live in their own home.”

Nick Danagher, ILF Trustee and Chair of the ILF Advisory Group

are very closely linked, as ILF users must normally receive the highest rate of the care component of DLA to continue receiving ILF payments.

We said that DLA or PIP could not alleviate all the barriers that disabled people face on its own. However, the extra financial support that DLA currently provides is highly valued by disabled people. For example, DLA allows access to leisure facilities that may cost double if service users have to pay for their PA's admission. Having weekly cash payments of DLA greatly helps to make these kinds of activities an affordable reality.

People with the highest support needs are those at risk of being unable to live independently and these are the people who we considered should receive priority of support.

Service users are becoming increasingly skilled in understanding and assessing their own needs and our users felt that their own expertise should not be lost from the assessment process.

Many ILF users would wish to have a single point of contact to advise on all the information they need, whether it be on the types of benefits they might be entitled to, social care funding available to them, or

advice and support on anything related to their disability.

We will continue to listen

We are committed to hearing your views and using them to improve our service and to feed into wider debates.

To make sure you have a chance to get involved we will continue to arrange our events around the country so look out for an event near you.

For more information about how you can get involved in consultations like these:

Email: funds@ilf.org.uk

Phone: 0845 601 8815
or 0115 945 0700

my life

ILF user Geoff Pick invites us into his world

“my ambition to improve services”

Geoff Pick tells living how he is improving services for the wider community

Geoff's take on life has always been about what he can do rather than what he can't. Since his diagnosis of multiple sclerosis (MS) made continuing with his career difficult, he has wasted no time in developing his skills and

learning new things. Indeed, he has been able to use his skills and experience to improve the lives of other disabled people.

Geoff said, “My ambition was to improve services for disabled people and thanks to the personal development I've undertaken, I'm doing just that.”

“I was able use my ILF funding with more flexibility than Direct Payments. It has helped me build the confidence to continue developing”, he said.

Geoff is involved in a wide range of voluntary work. He is currently a Director for the Sheffield Centre for Independent Living.

He also chairs Sheffield City Council's Physical Disability and Sensory Impairment Service Improvement Forum

“I used my first ILF award to attend a rock concert!” he said. “Now, I can decide whether I stay in or go out.

However busy Geoff is, he is able to use his ILF funding to help him meet his priorities.

Indeed, the flexibility he has enables him to get the most out of his funding and give him real value for money.

“Life is about what you give to it, not what it gives to you.”



An ILF User since 2003, Geoff would not have had the opportunity to achieve his goals without ILF funding.

Initially, Geoff studied for a National Vocational Qualification (NVQ) in social care to, in his own words, “keep me sane”.

His appetite whetted, he has continued with his studies and personal development.

Geoff is now qualified in a range of skills including service user empowerment and recruitment advice.



“My ambition was to improve services for disabled people. Thanks to the personal development I’ve undertaken, I’m doing just that.”

Geoff receiving his National Training Award in 2009

in your area

what's happening in and around your region

"You Tell Us" – Regional events for ILF users

During 2010/11 the ILF has engaged with users across the UK, meeting over 240 people at our series of regional events.

The meetings have enabled the ILF to visit all 12 regions with users being invited to attend from over 45 local authority catchments.

The "You Tell Us" events took place in the following areas: Worthing, Wrexham, Ipswich, Blackpool, Edinburgh, Belfast, Aberdeen, London, Cardiff, Nottingham, Newcastle and Birmingham.

The final meeting of this year's "You Tell Us" events will be in York on 24 March 2011.

What our users said

"The best consultation meeting I've attended in years" (*Wrexham*)

"The facilitation of the groups was very inclusive" (*Edinburgh*)

"Excellent and informative – and I felt we were listened to" (*Wrexham*)

"Thank you for trying to help by being open to change" (*Worthing*)

The ILF has spent the year talking to users all over the UK. Here's a summary of what you've been telling us

The meeting discussions mainly focused on the recent changes to the ILF. Our users were concerned about what was happening to their funding, and the effect of ILF funding restrictions and local authority cuts on their ability to live independently.

People were reassured by the Minister for Disabled People's statement that said funding for existing users was protected until 2015, and by the knowledge that the ILF is involved in discussions about reform.

Our users were generally worried that their funding would ultimately be reduced if the ILF's budget were transferred to local authorities. But some people saw transfer as a positive move if it reduced bureaucracy.

The most recent meetings have also included a discussion about the Joint Committee on Human Rights independent living inquiry.

We are encouraging our users to respond to the call for evidence, as well as collecting views for the ILF's own submission.

We hope to visit different towns and cities later in the year and will write to you about any upcoming meetings or you can contact the Liaison team on 0115 945 0700 or email funds@ilf.org.uk.

"One of the best and most interesting meetings I have attended"

A user's representative, Aberdeen

