



October 2012

## A Joint Response by Gateshead Access Panel and Disabled People Against Cuts North East to the Government's Consultation 'The Future of the Independent Living Fund'

### Introduction

1. Gateshead Access Panel (GAP) and Disabled People Against Cuts North East held a joint consultation meeting on Saturday 29 September 2012 that was attended by disabled Independent Living Fund (ILF) users and three family carers of ILF users with learning disabilities from the local authority areas of Newcastle upon Tyne, Gateshead, North Tyneside and Sunderland.
2. GAP has also held telephone interviews with ILF users and discussions with parent/carers and other disabled people who may have been eligible for Independent Living Fund payments had it not been closed to new applicants in May 2010. As a User Led Organisation, GAP decided to hold their own event because the ILF consultation did not facilitate representatives / advocates to attend the formal events.
3. The central message of this consultation response is that **we are opposed to the closure of the Independent Living Fund**. The people already receiving ILF we have spoken to are concerned that the Fund was closed to new applications before consultation with them.
4. We believe that decisions have already been taken, driven by both the government's Welfare Reform and Localism agenda, and the decision made by the Department of Health and Association of Directors of Adult Social Services a decade ago under the Blair administration to develop a form of Individualised Funding as a means of controlling the growth of the cost of social care. An idea that evolved through the In Control project into Personal Budgets and the Resource Allocation System.
5. The North American idea of Individualised Funding was initially

promoted in Britain by Steve Dowson, formerly a director of the learning disability campaigning charity Values into Action, and then supported by the National Development Team for Inclusion.

6. In a paper for the Canadian Roeher Institute in December 1999, Steve Dowson and Brian Salisbury defined Individualised Funding as “public funding that is allocated to the individual, based on his/her unique strengths and needs,

and placed under the control of the individual to enable them to live in [the] community as a full citizen.”

7. We believe the idea of allocating funding according to the needs of the disabled person themselves is correct, and that this should be flexible and not be tied to one type of service or location. Disabled people should be allowed to live ordinary lives and enjoy the full benefits and rights accorded to their peers. This is the central approach of section 2(1) of the

## **What is the Independent Living Fund?**

**The Independent Living Fund, or the ILF as it is usually referred to, was set-up by the government in 1988. The Disablement Income Group was involved from the start and nominated 5 of the Fund’s 10 trustees. It gave substantial funding for the first time directly to severely disabled people to employ someone to help or assist them with personal care tasks at home and in the community or buy services from an agency.**

**It revolutionised the social opportunities of a generation of severely disabled people. People who in the past had had to spend their lives in residential care, could now be parents, care-givers, workers, students, volunteers, partners, and campaigners. People with severe learning disabilities could get the support they needed to live in the community or stay with their families – freeing many of them from the inhumane and abusive treatment of the past.**

**The Fund was closed to new applications in May 2010. Disability organisations in the north east are beginning to see the detrimental impact this is having on the lives of some severely disabled people.**

**If the Fund is closed and transferred to local authorities, the maximum expenditure policies being introduced by some local councils, with the support of directors of social services, will mean imprisonment in residential care for some who now live independently and need 24/7 support.**

Chronically Sick and Disabled Persons Act 1970 that was passed by Parliament following a campaign by the disabled-led Disablement Income Group (DIG), with the active support of MPs Alf Morris and Jack Ashley.

8. In her judgement in the Supreme Court case involving the former prima ballerina Elaine McDonald that was published on 6 July 2011, Lady Hale wrote it is “quite clear that section 2(1) of the Chronically Sick and Disabled Persons Act 1970 was intended to create an individual right to services if its criteria were met”. The difficulty for disabled children and adults and their families is that local authorities due to central government funding constraints have always failed to meet this statutory duty.
9. When the Independent Living Fund was set-up in April 1988, its creation reflected the inadequacy of the two-tier Attendance Allowance care benefit where disabled children and adults of all ages were given a common funding allocation for the cost of their day and night support. DIG themselves recognised in a 1987 policy statement that there was a need for “a third rate of attendance allowance, substantially higher than the rates presently payable, ...to enable even the most severely disabled to buy the help they need to live outside institutions. As with the existing attendance allowances, this should be payable to the disabled person, thus

**Statistics show that the biggest rise in welfare funding in recent years is the cost of younger disabled people’s care, not older people’s as many people think. Current moves through commissioning by local authorities at a local level to reduce costs will force young disabled people to choose between a life of restriction in their homes with limited help from their family, friends or neighbours or moving into residential care. Independent Living Fund users and their families require support and reassurance from the Government that this is not to be the only ‘choice and control’ they will have in their lives**

giving disabled beneficiaries a measure of control over their own lives.”

10. From the start, the Independent Living Fund’s approach to assessment reflected the need for a more personalised approach than Attendance Allowance that was consistent with the individual rights of section 2(1). Throughout its existence, the Independent Living Fund has used independent social workers to assess each person according to their needs and then identify the individual cost of care or personal assistance required to meet that need within the financial constraints and upper limits of the Fund. This meant that once a detailed assessment had identified each hour of personal care support that was needed,

the cost of meeting this through a domiciliary care agency or direct employment of a personal assistant or funding additional support in Independent Supported Living schemes was identified from person to person.

11. The closure of the Independent Living Fund will mean the loss of such a personalised, needs-led approach to the assessment and provision of services to severely disabled people. Much is made in the DWP's consultation document of the statutory right to personal budgets that will be introduced in the new social care bill due to be published next year. But personal budgets is essentially an administrative, resource-led approach to the assessment of social care needs that all but removes the involvement of traditional social work assessment except for those with the most complex needs.

12. When the review of the Independent Living Fund carried out by Bob Hudson and Melanie Henwood was published in January 2007 it recommended "the ILF should be fully integrated with personal budgets rather than existing as a parallel system of social care funding". This recommendation was made at a time when personal budgets were only being piloted in 13 local authorities. In effect, this review recommended a proven model that worked for thousands of severely disabled people should be replaced by an experimental idea that still has major teething problems.

13. A lot is made of the 'choice and control' personal budgets gives people, but in the current financial climate the Resource Allocation Systems associated with personal budgets and personalisation are being used by local authorities to reduce the care packages of disabled people of all ages who have previously been assessed by a social worker as having a particular set of needs. The social care system has for more than a decade given disabled people and family carers a right to know the cost of care and use direct payments as an alternative to local

**The Independent Living Fund allowed me to attend functions, concerts and the theatre and do things that I would not otherwise have been able to do. It made me INDEPENDENT. At home it allowed me to do things the way I wanted them done including eating what I wanted to eat.**

**I can't imagine anything positive coming from the closure of the Independent Living Fund. There is a danger disabled people will be viewed as dependent and a medical problem. Closure will undermine disabled people's independence and will further the discrimination we have fought against for so many years.**

**Paula Greenwell, former chair of the Northern and National Disability Arts Forums**

authority services, therefore there has been 'choice and control'. To associate such language with a new system that is designed to reduce or remove social services from those who need it is disingenuous and unfair to some of the most disadvantaged and vulnerable layers in our society.

14. The Department of Health, Department for Work and Pensions, Care Quality Commission and its predecessors, and the Association of Directors of Adult Social Services have searched since the 1990s for a way to control the cost of social care. Instead of encouraging an open debate in our society about its priorities and responsibilities to disabled children and adults and their families and the need to find the funding to fully implement the section 2(1) statutory duty, the organisations tasked with safeguarding the most vulnerable in our society have done exactly the opposite.

15. The closure of the Independent Living Fund is part of a process that will lead to the repeal of the section 2(1) duty and the Chronically Sick and Disabled Persons Act. At a time when the World Health Organisation and World Bank's 'World Report on Disability' is recommending governments and civil society should 'enable access to all mainstream policies, systems and services', 'support people to live and participate in the community', and "provide services in the community, not in residential institutions or segregated settings', the very opposite

may happen in Britain for the most severely disabled people.

16. The search by one local authority for ways to reduce costs led to the Supreme Court decision in the Elaine McDonald case in July 2011 that it could set a financial cap on that person's care. This judgement is starting to be used by local councils to limit the care of severely disabled people. With funding limits being set at the cost of nursing or residential care, the transfer of full responsibility for severely disabled ILF users to local authorities will see the return of forced institutionalisation for some with 24/7 care packages that far exceed these limits.

## **28 July 1988**

**When the Independent Living Fund was set-up in April 1988 it was established as a discretionary trust.**

**Disabled people led by the British Council of Organisations of Disabled People wanted a Fund that gave severely disabled people a statutory right to personal assistance. They demonstrated for this in London on 28 July 1988, and for rights instead of charity.**

**This event gave an emerging and growing movement the confidence to campaign harder for disability and independent living rights.**

## **The Department for Work and Pensions Approach to the ‘The Future of the Independent Living Fund’ Consultation**

17. Three people who attended our consultation also attended the DWP’s consultation event in Newcastle upon Tyne on 8 August 2012. This was organised with the help of the Independent Living Fund’s senior management and trustees. “Summary notes” of the DWP event were sent to participants on 27 September 2012. These are essentially an aide memoire so those who had attended can complete the government’s online consultation on their own. Two people who discussed the DWP event at our consultation event on 29 September found these notes to be a limited record of what took place.
18. We question why this approach has been taken given people attended the DWP event from as far away as Manchester, Carlisle and Berwick. We believe it is reasonable to expect that when 25 family carers and disabled people who use the Independent Living Fund make a significant effort to attend a government event that this is reciprocated with at least a full record of what went on.
19. We believe the failure of the DWP and ILF to produce a combined report of the 14 consultation events also reflects their unwillingness to show the collective opposition to the closure of the Fund among ILF users and their families across Britain, and the DWP’s fear of an open

debate about how to approach the support needs of severely disabled people in the future.

20. The specific criticisms of the DWP and ILF’s “summary notes” include:
  - They fail to reflect the disquiet of some family carers and ILF users at the beginning of the meeting when a young DWP policy officer said no decision had yet been taken to close the Fund.
  - When the first consultation question was raised, the family carers present almost to a person raised objections about the integrity of the question because it steers respondents towards the idea the Independent Living Fund should be closed and ILF users care packages be provided through local authorities. The “summary notes” omit this.
  - Disabled people and family carers present expressed support for the continuation of the ILF because they trust it in contrast to their local authorities. The “summary notes” do refer to the opposition to closure, but then are written in a way that suggests people are rejecting the idea their needs should be met within the “mainstream care and support system” run by local authorities. Given the multiple tiers of personal assistance funding which include local authority social services, Access to Work, the Independent Living Fund, Disability

Living Allowance, education allowances, children's services and health funding, it is misleading to suggest opposition to the closure of the ILF is because disabled people and family carers reject being part of a mainstream system when that system does not exist in the first place

- One person raised that both the review of the Independent Living Fund and the DWP consultation failed to mention Professor Colin Barnes proposal in 2004 "to take the distribution of direct payments out of the hands of local authorities and centralise it. This could be achieved by setting up a new national body accountable directly to the National Centre for Independent Living." This is omitted from the "summary notes". We believe this is because its presence would turn the debate away from the closure of the ILF towards the considerable merits of its retention and expansion into a national independent living scheme that would free disabled people of all ages from the uncertainty of local authority provision.
- One family carer raised that if the ILF is closed there should be a contractual agreement between the user, ILF and their local authority to protect their funding in the medium to long-term. This specific idea is omitted.
- One person asserted in very clear terms that if the DWP and government

**The Independent Living Fund has cushioned the blow of the local council budget cuts towards my care package. Without the ILF I would be up a certain creek without a paddle. I find the proposal to close the Fund surprising because the ILF was brought in by a Conservative government.**

**The ILF increases my ability to be independent and supports my 24/7 care package without which I'd be lost. There will be nothing positive about the closure of the ILF. It will be detrimental to the well-being of thousands. In my personal opinion people who rely upon the ILF will suffer and the worst hit will die!**

**For me, I could not rely upon my local authority funding alone to maintain my health. Closure of the ILF will have a grave effect on both my physical and mental health.**

**Charles Cuppage, a university technician**

listen to the advice of Disability Rights UK it will create difficulties for them and move disability policy in the wrong direction. This is omitted from the notes.

- One table in the final discussion put forward the idea of the retention and expansion of the ILF as an alternative to the government's proposal, and the need to debate the merits of other systems including the Norwegian Uloba scheme and the Swedish

cooperatives for independent living.  
Again this is omitted from the notes.

21. We believe the approach of the DWP and government to this consultation demonstrates a decision has already been made to close the ILF. For us, the following facts about the consultation process reinforce this impression.

- There is no equality impact assessment – this avoids the need to discuss the ILF’s history, policy implications and practical examples of what closure would mean. Each ILF user is subject to regular reassessments so it is easy to identify what the loss of ILF funding would mean in 19,000+ cases. In October 2010 when the United Kingdom Disabled People’s Council met with Maria Miller MP they emphasised the importance of disability equality impact assessments.
- The ILF itself has organised the consultation meetings at the behest of the DWP. We believe the ILF’s trustees are in conflict with their fiduciary duty to defend their beneficiaries’ interests and actively oppose closure.
- Consultation questions steer respondents towards the option of closure and transfer of responsibility to local authorities.
- There is no discussion of the option of a national Independent Living Fund under disabled people’s control free of political interference that provides one

source of personal assistance funding as of right for all disabled people irrespective of their age.

- The shortest possible timescale for the consultation of 12 weeks has been adopted.
- Only 14 consultation meetings have been organised across the UK with very limited numbers. These have given less than 2% of the ILF’s 19,000+ users the opportunity to attend, a figure that falls well below 1% if family carers are factored in.
- The Easy Read document gives no practical examples that set-out what closure of the ILF would mean, an essential step for disabled people who find comprehending abstract ideas difficult. Given that about half of the Independent Living Fund’s users have a severe learning disability, we believe this is a serious omission that introduces a fault line into the consultation process for what is one of the most vulnerable layers in our society.
- ‘The Future of the Independent Living Fund’ is an English consultation document for a UK-wide fund – there is no discussion of a scenario where national independent living funds are set-up in Wales, Scotland or Northern Ireland while there is transfer of responsibility to local authorities in England.

## **Individual Comments Made by Consultation Participants about the Possible Closure of the Independent Living Fund**

22. Everyone felt the Independent Living Fund has had a positive impact on their lives, including supporting their ability to live independently from their families, maintain paid employment, be a parent, carry out voluntary activities and represent the needs of disabled people in a variety of organisations, and so on. For two people present who have 24/7 care packages there was a fear the closure of the ILF would lead to them eventually being placed in residential care.

23. There is a fear among ILF users and family carers about the impact the closure of the Fund will have on them. The parents of a man with severe learning difficulties were very worried about the current situation. They feel it is best that he is supported to live at home with them as they can ensure his support needs are met in the right way. The ILF funding they receive helps them to achieve this now. Social workers have raised the idea of their son living elsewhere but they are opposed to this.

24. Concerns about what will happen if and when local authorities assume full responsibility for ILF users stem from

### **The difference the Independent Living Fund has made to my life**

**The support I have received from the Independent Living Fund has allowed me to self-manage my own support extremely effectively and empowered me to be in total control of my life.**

**My personal assistants support me with everyday tasks that if I were to attempt to do on my own, would be likely to lead to fractures due to my condition. My health has been good since my support package has been in place and I am confident that this has allowed me to avoid being admitted to hospital and many visits to A&E.**

**The ILF's flexibility has enabled me to appoint an agency to handle the administration and pay roll, and most importantly for me, the protection of not employing a whole staff team.**

**Combining funds from the ILF, Direct Payments and Access to Work has allowed me to remain employed full-time, meaning that I own my own property and am not reliant on any other benefits. I know that the ILF has enabled me to progress professionally, maintain my financial and physical independence, social and family life.**

**Angela Stewart, a full-time worker with a disability charity**

- people's personal experiences. One person prior to getting ILF had lived in very difficult circumstances because they had been told they did not qualify for services. They fear a return to such a situation for others with a similar condition, particularly where professionals make a mistake about entitlement and fail to acknowledge they are wrong. Also, at times some people feel it is a game when they are dealing with social workers because they sometimes have an agenda that is not always clear. One person found out about their social services long-term plans for their son when a social worker let slip a piece of information in conversation. Local authorities are complex organisation with lots of competing priorities where the needs of severely disabled people can suffer. If local authorities had been able to meet the needs of severely disabled people there would not have been a need for the ILF in the first place.
25. The point was made that local authorities under personalisation and personal budgets are considering what they call 'natural support' as an alternative way of providing care and support. By this they mean family, friends and neighbours. There is a concern that if the ILF is closed then local authorities will push this so-called 'natural support' as an alternative to professional but costly care workers or personal assistants, however unfeasible this might be.
26. There was a concern expressed by one person that some severely disabled people with costly care packages will be gently encouraged to go into residential care. The central ethos of the Independent Living Fund is that it supports disabled people to live independently in the community and this is a condition of its funding. Removing the ILF and the culture it promotes would mean there could be a return to the routine institutionalisation of some adults, and the withdrawal of support and assistance from many others living in the community that currently allows them to lead an active life.
27. The abuse of disabled people in residential care that has been highlighted recently by Panorama investigations is a concern to severely disabled people. One person who had gone into a home when their care package broke down due to holidays and illness among their personal assistants found the experience difficult as they were not washed properly, the food was of a low quality and the place smelled of urine. Other long-term residents had very limited expectations and appeared to be going nowhere. One other person made the point that if as seems likely the government believes it is acceptable now to institutionalise those with expensive care packages they will make a lot of effort to show they are addressing safeguarding issues in residential care by increasing inspections.

28. One person demonstrated the impact the closure of the ILF to new applications has had. Prior to going into hospital for more than a year, they had been an ILF user and had led an active and independent life thanks to the Fund. When they came out of hospital they could not access the ILF again, therefore their care package was reduced significantly compared to what had previously had despite their progressive condition getting worse. They feel they have no control over their life and have to ration their time including at our consultation event where they had to leave in the middle because they did not have the support they needed.
29. Two people attended the event who would have in the past have been able to access the Independent Living Fund as their conditions have deteriorated recently. One person feels the financial pressure on councils means councils are reviewing and reducing care packages, even if someone's needs mean they need more support. One other person had been advised in the past against applying for the higher rate of the care component of Disability Living Allowance which was one of the qualifying conditions for the ILF, and felt when they did qualify that their social workers could have been more proactive in supporting an application to the ILF.
30. Questions were raised about what the approach of the Care Quality Commission is towards the closure of Independent

Living Fund and that they have a responsibility to safeguard and protect disabled people and family carers. The consensus was that a meeting should be arranged with the CQC in the north east to ask them about this.

31. One person's social worker had told them that things are going to get very difficult for severely disabled people and that they need to campaign now to stop what is about to happen.
32. One person summed up what everybody was expressing when they said they just want an ordinary life, and this is what the ILF gives them.

**The ILF and my other care funding enables me to be involved in a gardening project, get out and about in the community, go away with my personal assistants to see my brother, not put pressure on my elderly parents to care for me in their old age, go to planning groups and do voluntary activities such as peer mentoring, and go to a stroke support group and the gym at my local leisure centre. It gives me a life.**

**Without the ILF my care package would be cut in half. I have already experienced a cut in my local authority care funding. If the ILF closes I fear my impairment and illness will get worse as I will not be able to take a short break. My condition is difficult to manage and my health can deteriorate quickly. I need the care package I have now.**

**Anna Mace**

## **What We Think of the 3 Options for the Independent Living Fund's Future**

33. Because the DWP's consultation document 'The Future of the Independent Living Fund' steers respondents towards accepting the provision of all social care through local authorities when referring to a fictitious "mainstream care and support system", we considered the 3 options available for the future of ILF users and their families.

34. They are: (1) ILF closure and the transfer of resources to local authorities without protection; (2) ILF closure and the ring-fencing of funding for individual care packages; and (3) keeping the ILF and.....

### **35. Option 1 - ILF closure and the transfer of resources to local authorities without protection**

- There is a fear that if the Independent Living Fund's resources are given to local authorities there will be a repeat of what happened with the Independent Living Transfer between 1993 and 1996. £230 million was given to councils across Britain to support the needs of severely disabled people. This was in the wake of the introduction of changes to community care law in England and Wales, and the launch of a new Independent Living Fund 1993 that required £200 a week of local authority services before an application could be made. The

enormous inconsistencies in the uptake of the ILF today stem from the different ways local authorities spent this £230 million. The best ring-fenced the money for severely disabled people as intended and supported ILF applications wherever possible, while others used it to cover shortfalls in general budgets or to fund local initiatives. The fear is the same will happen again.

- It was suggested by one person that while ILF users might keep their funding for several years, apparent inequities between former ILF users and other service users will mean the former will see their services reduced over time, and their funding absorbed into general budgets.
- Government policies are squeezing the rights of disabled people. An example of this was the decision by Kensington and Chelsea council to insist the former prima ballerina Elaine McDonald should use incontinence pads instead of have a worker to help her use the toilet at night. This case had arisen when Elaine's council had mismanaged an ILF application that subsequently failed. They preferred to undermine her dignity and human rights than find the funding to support her full needs. Councils will try to find cheap ways to meet severely disabled people's needs, including putting

- pressure on people to use family, friends and neighbours.
- Social workers are facing increasing pressure to assess a person's needs according to the available budget and resources rather than what the person actually requires. Unless the social work profession speaks up now to oppose the closure of the ILF, they will end up taking a resource-led approach to severely disabled people if the ILF closes with disastrous consequences for many people's lives.
  - Rules introduced three years ago as part of the government's Fairer Charging policy means local authorities can assess a person's entire Disability Living Allowance care component as being available to pay for services. Currently the ILF only requires half of this benefit to be used on a person's care package.
  - ILF users are small businesses with some people at the consultation event employing up to 8 personal assistants where they have a 24/7 care package. If ILF users lose their funding this will lead to many workers being made redundant. Also, domiciliary care agencies will be affected by the loss of business if and when ILF users lose their funding. There were questions raised about whether domiciliary care agencies have been consulted.
  - One local authority is claiming when reviewing care packages they have been 'over generous' due to the fact that they were a pilot for Individual Budgets. This will happen to ILF users if transferred to local authorities on the grounds of equity. Local authorities have no qualms about shifting the goal posts in their favour.
  - Costs are being driven down by local authority and health commissioning processes locally and this can impact on care packages. For those ILF users with large care packages, after the ILF is closed pressures to cut the cost of residential care could reduce the funding level at which local authorities will decide a severely disabled person should be forced into residential or nursing care rather than be helped to live independently.
  - ILF users can choose their own care agencies at present, but local authorities can limit the choice available to service users if they want.

### **36. Option 2 - ILF closure and the ring-fencing of funding for individual care packages**

- If ring-fencing was put forward by the government as an alternative to closure of the ILF, this could be done in two ways. Either ring-fence each person's care package individually or ring-fence the current ILF funding for

each area. Individuals prefer the former as a very minimum if the ILF is closed, and this needs to be a contractual agreement with long-term guarantees in writing.

- Even if a person's ILF money is protected in the medium to long-term it does not mean there are guarantees their local authority funded assistance will stay at the same level.
- Protecting ILF users funding will produce inequities at a local level that some people might use in the future to undermine any ring-fencing of ILF funding.

### **37. Option 3 - Keeping the ILF and.....**

- Retaining and expanding the ILF could mean that disabled people of all ages are treated the same in a single cohesive social care system – the ILF could provide all the funding for a person's care package and free them from the complexities of the current multi-tiered funding system.
- The social isolation of older disabled people could end with all the health benefits this would bring.
- Personal assistants and care workers could be given the same pay, pension and sickness rights as civil servants and other statutory workers if central government increased the funding made available to the ILF.

- Expanding the ILF and removing any upper limits to care packages could end the uncertainty many severely disabled people feel in their day-to-day lives.
- There could be a recognition for the first time that disabled people of all ages should be supported as of right
- Expanding the ILF could mean that policies intended to protect severely disabled people that have been ignored by central government and local authorities could finally be addressed. In particular the coordination of health and social care for those with very complex conditions.
- Disabled women forced to use incontinence pads by their local authorities could be given the funding they need to have workers overnight to protect their dignity and human rights.
- The ILF could be self-organised and severely disabled people be freed for the first time from the machiavellian and underhand approaches found in statutory services where rationing is coupled with the low priority of those with complex health and social care needs.
- Independent assessments and self-assessments that are purely user-led could be used to determine a person's needs.

## Our Conclusions

- a) The Independent Living Fund should be retained and opened to new applications immediately with an increase of funding in 2013/14 and 2014/15 to £700 million and £1 billion respectively to enable severely disabled people of any age to be able to apply.
- b) The original age criteria used when the Independent Living Fund was opened in 1988 should be restored so that the parents of disabled children have the resources to pay for personal assistance so that no parent has to consider putting their child into care.
- c) The individual rights to assessment and service provision in the statutory duty in section 2(1) of the Chronically Sick and Disabled Persons Act should be retained and fully implemented – we believe the needs and human rights of disabled people and their families need to be safeguarded and protected even in difficult financial times.
- d) All disabled people should be given the statutory right to live independently with full support that is identified through self-assessment or a needs-led assessment carried out by a social worker or independent living advisor from a centre for independent or inclusive living.
- e) The recommendations of the Winterbourne View serious case review that affect people with learning disabilities should be fully implemented.
- f) The World Bank and World Health Organisation's recommendations that governments should help disabled people to 'enable access to all mainstream policies, systems and services', 'support people to live and participate in the community', and "provide services in the community, not in residential institutions or segregated settings' should be adopted in the United Kingdom and a national plan produced to identify how they will be implemented.
- g) The DWP should stop asserting that the ILF was only ever set-up to help 300 people when they know the Disablement Income Group expected it to help 1500, and the Disability Alliance thought this would be several thousand. In 1988, the ILF trustees produced 55,000 leaflets and 16,000 posters to advertise the ILF.
- h) The DWP's 'The Future of the Independent Living Fund' consultation should be abandoned as it is not fit-for-purpose, and an independent review should be carried out into why such a flawed document and process was agreed in the first place when it involves the interests and future of some of the most vulnerable people in society.
- i) A new review of the Independent Living Fund and social care in general should be carried out under the direction of the independent living rights movement before there is any further consideration by Parliament of changes to social care legislation.

# My Experience of Social Care by Ian Atkinson

I was one of the first people in Gateshead to receive Direct Payments to employ Personal Assistants. At the time I lived with my parents, and used Direct Payments as an introduction to Independent Living. This was in 1998, aged 27.

At that time I was in receipt of DLA at the middle rate care component, which meant I didn't qualify for the ILF. My first assessment for Direct Payments resulted in 8 hours per week Personal Assistance to assist me gain a social life, and to support me to go swimming.

Soon after that I became the first person in Gateshead to receive a Direct Payment to assist me in my role as a volunteer. Long term, this assisted me in gaining skills to enter into paid employment, where I then received PA support via Access to Work for the whole of my working week (28 hours).

In the summer of 1999 I received support for Respite Care in the form of a Direct Payment. This meant employing Personal Assistants to work with me in my parent's home, meaning that my parents were able to go on a holiday for the first time, without me.

However, it was at that time that I began to question whether I ought to be claiming the Higher Rate of DLA. I reached this conclusion

because of my sister needing to come over to stay with me overnight for Fire Safety/Emergency Egress reasons.

However, the advice that I was given by my Local Authority's Welfare Rights Officer was that it was unlikely that I would qualify and rather than encouraging me to try for the Higher Rate he focussed on the possibility that I may be reduced to the Lower Rate of Care. As this had happened to me due to a 'clerical error' in the mid 90's he did put me off from applying.

Had I received the Higher Rate of DLA it would have opened up avenues to receiving ILF, although I might have still not qualified at that time, as my Care Package may have still have been below the £200 a week threshold. My Local Authority was paying PA's only £5.25 in the early days.

At that time my PA was doing his Social Work degree and as part of his studies he found that my Local Authority had the lowest pay rates in the North East region. (To my knowledge they still are the lowest, now at around £7.25 per hour, a £2 increase in 14 years).

In January 2006 I moved into my own place.

My care package became 54 hours per week, and I still received 28 hours per week PA support via Access to Work. Yet despite acknowledgement that I needed a total of 82 hours per week, my Local Authority's Welfare Officer still warned me against applying for Higher Rate of DLA, as he questioned my night time care needs.

In 2009 my Supported Employment Officer from Scope offered me a Benefits check. She was astounded that I did not receive Higher Rate of DLA, and assisted my application, to find in 2010 I did indeed qualify.

However by the time I'd qualified and then waited for my Local Authority to make a referral to the ILF, I had missed the May 2010 cut-off date for new claimants.

In the past 12 months my Personal Budget has been reduced by 8 hours per week, despite my condition not changing. My Local Authority's justification for this reduction in my assessed care needs was that they had been 'Over Generous' in my assessments for the previous 5 and a half years.

(Very careless of them to be 'Over Generous' with public funds for so long. Especially as I know that they had been 'Over Generous' with numerous other Care Packages during the same period of time!).

I think I'm right in understanding that this would not have been so easy for my Local Authority to do without agreement from the

ILF, had I been able to claim what it seems I'd been entitled to in the first place?

What would I have gained via ILF?

This is a difficult question to answer, having never received ILF. That said, I do know that certain aspects of my care and support needs are omitted from that provided by my Local Authority.

Examples include:

- Swimming – Whilst I am assessed within my Personal Budget as needing support to go swimming or access a gym, this is for 1 hour per week. This is to include preparing a bag, travelling to and from my most local accessible pool, assistance in getting changed, assistance to get in and out of the water and support from a PA in the water to actually swim.

I argued that this is not enough time and calculated that I need at least 3 hours.

I was reminded about being flexible with my assessed hours. I have tried being flexible for 5 years but the hours are not enough to enable me to go swimming. To be 'flexible' would mean 'doing without other assessed needs', such as meals, personal care or housework. As a result, I never go swimming or to the gym.

- Other support needs not covered under my care plan include: assistance to help me wash and maintain my van which is essential for work and help needed to fill her with diesel; assistance clean windows at home; help when I want to do some gardening; and going to the doctor or dentist for routine health checks.

Also in recent Care Reviews the assessment criteria changed. I no longer qualify for support to take a short break. Previously I could claim some costs when going on a holiday where I was charged extra. For example I would go on holiday with disabled friends to 'specialist hotels' where care, support and physiotherapy were available. Such accommodation costs more but this was achievable through my Personal Budget. I'm uncertain that I could have used ILF in that way, but I do have friends who used ILF to fund PA Support on holidays.

Overall and looking back now, I do feel I may have received a more holistic Care Package had I qualified for ILF in 2006. However, looking ahead, if the ILF closes in 2015 as proposed then I fear this will still have a detrimental effect on my Care Package as the knock-on effect will squeeze Local Authority social care budgets.

Therefore, the ILF Consultation really ought to have incorporated ALL disabled people and their family/carers who rely on Health and Social Services to support their Independent Living. (So back to the drawing board? Doubt it.)



"I cannot envisage 2015 if suddenly the Independent Living Fund is taken away. It would probably mean me having to go back into residential care, which I thought I had got out of in the late 1970s."

John Evans, Evidence to the Joint Committee on Human Rights in 2012

John is a leading activist in the European Network on Independent Living and the European Disability Form. ILF users in the north east believe it is shocking that such a respected and influential figure should be expressing these fears.

## **How the Independent Living Fund changed my life**

Before I received support from the Independent Living Fund, I had lived in the community without help for a number of years after graduating from university. My council had initially said I was not entitled to social services from them because I was not 'ordinarily resident' there. They said I was the responsibility of my home county that was on the opposite side of the country, and who I had never received services from.

I have a progressive condition, therefore while I managed at first I ended up relying on my neighbour to help me up off the floor when I fell from my wheelchair when transferring between my bed or toilet. I was never able to cook a meal in my flat because there were no adaptations, and I had difficulty making hot drinks. I did have a Motability car, but I relied upon strangers to lift my manual chair into the boot and push my body back into the seat and lift my legs in the vehicle. When asked, it is incredible what people will do. I got the collection of benefits, banking, buying sandwiches, shopping and so on off to a fine art from my car. Prior to finally getting an assessment of need, it took me four to five hours on a morning to get ready, and the police even had to break into my flat twice to lift me off the floor. Because my condition meant I could not control my falls, my head usually hit the thin carpet covering the concrete floor first.

After four years I was given funding for services by my council. These have always formed the core of my care package and met my critical personal care needs at home. With the additional support I received from the Independent Living Fund, my life started to change for the better, particularly my ability to work and develop a career. My personal assistance allowed me to lead an active social life and travel around the country. It also meant I could be actively involved in disabled people's organisations, and for many years I chaired a disability arts organisation.

Most importantly for me, the Fund gave me the additional support I needed to be an active parent. While the Fund has never funded specific support for the children of disabled parents, my son was able to be safely with me when I was being assisted by one of my workers. The benefit of this has been immeasurable. My son has never been a young carer and cannot perceive of a situation where a disabled parent would have to rely on the labour of their child for essential practical and emotional support. He has grown up with the normal expectations of his peer group and will enter University and adult life next year. If I had had to live in a residential or nursing care home, being a parent or having a professional career would not have been possible.

**Stuart Bracking, a retired local government worker**

# My Love Affair with the Independent Living Fund

By Mary Laver

My love affair with the Independent Living Fund (ILF) started over 25 years ago. I was just 40 and I am now 65. When it came into my life, a life that I was existing not living, a life that since becoming disabled with Rheumatoid Arthritis at the age of 40 and within 12 months stopped me leaving my bed for the next 2 years.

I found myself in the position that I could not weight bare on my legs or feet, and my arms very quickly bent making it impossible to get out of my bed and into my power chair. My care from social services was very basic, 2 hours per day, and all but 2 of my friends had deserted me. I watched the seasons change by the reflection in a picture I had on the wall opposite my bed, which by this time was now in my lounge. Life was very grim until my social worker told me about the ILF; my love affair was to begin.

Being introduced to the ILF was not easy, my social worker had to fill in a long and complicated form and then we just had to wait for the verdict, yes or no to me getting the ILF. You can guess it was a yes.

While waiting for the verdict, it was a long time coming, I decided to sell my house and buy a bungalow. This I did from my bed. By the time the ILF was confirmed, the sale had gone through and I was on the move to my new home and my new life with my ILF.



I will not bore you with all the life changes over the past 25 years thanks to the ILF, but I will jump straight to 15th June 2012 at 5.03 pm in Newbridge Street, Newcastle and a crowd eagerly awaiting the Olympic Torch to approach because that was the date, time and place that I was to have the greatest honour of my whole life. I was to carry the Olympic Torch in recognition of my charity work.

The list is long and you can Google me to find out more, but highlights are I drove my power chair from Lands End to John O'Groats making it into the Guinness Book of Records. This I did for the Royal British Legion. I have spent for the past 22 years two weeks each year selling poppies, I have been pushed in

my manual chair to raise monies for various charities in 16 Great North Runs. The list goes on. None of this would have happened without the ILF.

My life does not all evolve around good works. My ILF enables me to go out for long walks with my two much loved Jack Russell's, Jack and Molly. My ILF enables me to visit places of interest, to have the freedom to do what I want, when I want, with whom I want. I also use the ILF time for my carer to take me to my hospital and doctor's appointments.

In all to sum up I would say I lead a life full of challenges and wonderful experiences mixed up with the odd boring moments.

If I am divorced from my ILF I will be living a life of hell in my beautiful bungalow. My JRs will have to find a new home, my social life will disappear. How do I know that? I know that because I have seen my care package without the ILF. Per day, I will receive 1 Sleepover, 1 hour lunch, 1 hour tea. Per week, will be added 7 hours social activities, 90 minutes shopping, 45 minutes housework and 20 minutes ironing. I nearly forgot 2 showers of 15 minutes each.

Under the Governments 'Fair Access to Care Services' Policy (FACS) which are the guide lines that my council use to determine all care needs, I would see my future as sitting all day at my home in my power chair from 0745 to 2230, with only two breaks on my bed to enable me to be washed as I will be wet from having no midmorning and afternoon call. This washing time would be taken out of my 1 hour lunch. In that lunch time I am told that I will receive a sandwich, a hot drink and be toileted; the 1 hour tea time call, I am told that I am to be given a

warmed up meal – when that meal will be cooked and by whom I know not - a hot drink and be toileted, and not forgetting washed and changed. By the time the night staff come on at 2200, I shall again be wet so will need to be washed and changed as well as be given a hot drink and put to bed at 22.30.

Due to this appalling care package, open pressure sores will soon appear that will need to be treated by a nurse on a regular basis. I see my day as me sitting in a wet pad; just being fed and watered; no Jack and Molly to keep me company, and above all no freedom to do anything I wish. My home will be my prison.

I must not forget my 7 hours of social care per week, what am I going to do with that? I could use it to have one day out or add 1 hour per day to my lunch or tea time call.

Being very dramatic, there is a pond at the bottom of my garden and if I final mentally snap and can take no more of this appalling care, it would only take a few minutes and all my problems, and that of the government, will be sorted, or I could get someone to leave my gate open - I cannot do that myself - a short metro ride would see me on a short pier where I could take a long walk.

The other alternative would be a care home. Would the people who are taking my ILF away care to live in a care home, the pond seems more inviting.

So there you have it, my love affair with the ILF. **I will fight with every breath in my body to keep this affair going on.**