



**A Consultation on the future use of
resources devolved following the
UK Government's decision to close
the Independent Living Fund**

**Response of the Glasgow Centre for Inclusive
Living**

November 2013

1 Introduction

- 1.1 **Glasgow Centre for Inclusive Living (GCIL)** is an organisation which is run by and for disabled people (i.e. a Disabled People's Organisation or 'DPO'). GCIL provides a range of services which aim to help disabled people challenge the barriers to independent living. These include a variety of employment, housing, training and self-directed support (SDS) services.
- 1.2 This response draws on our extensive experience (17 years) of providing support to people using direct funding in various forms (direct payments, Independent Living Funds (ILF), self-directed support etc). GCIL's two inclusive living support services, which operate in Glasgow and East Dunbartonshire, currently work with around 600 people per year between them.
- 1.3 In addition the response is informed by feedback from a consultation event with GCIL service users, including both those in receipt (90%) and those not in receipt (10%) of ILF funding. Forty people attended the ILF consultation event on 26 August 2013 at GCIL. There was a wide and varied response to the questions posed in the consultation document.

2 Joint Statement

- 2.1 GCIL supports the following joint statement from Disabled People's Organisations

'The money available from the ILF supports disabled people to participate in society and lead an ordinary life in a way that funding for social care based on other criteria and delivered by LAs does not. Therefore, disabled people and their directly accountable organisations call upon the Scottish Government to:

Protect existing users – you cannot empower one group of people by disempowering another already disempowered group.

Meet new demand, firstly, from the money that becomes available through attrition from the existing resource, and in the longer term, find new money to address this demand.

Replicate existing ILF policies: eligibility criteria, accountability mechanisms, portability, flexibility and staffing expertise in Scotland.

Administer the funding nationally, through an independent trust.'

3 Responses

Question 1: What aspects of the current ILF worked well and what elements did not work so well?

What has worked well?

- 3.1 There was unanimous agreement that the ILF was a vital source of funding and, in the main, had been administered very effectively. Participants felt the ILF provides more individual choice and flexibility:

ILF was about allowing you to live your life in the way you choose – much more flexible than the Local Authority

ILF recognises your right to have a life, not just survive!

- 3.2 It enables people to have a better quality of life:

I would be lost without ILF - it allows me to continue living in my own home, as they pay for sleepovers

The money allows me to have a “normal” life.

I could work because of ILF funding.

As a result of ILF funding I am more involved in my local community and don't feel as isolated. Local Authority only paid for basic care.

If I did not have this funding I would be stuck in the house again.

- 3.3 People liked the portability of the ILF as it is...

...a national source of funding and the criteria applies regardless of where you live

- 3.4 GCIL believes that the ILF has provided a significant and valuable source of support in enabling thousands of disabled people to have improved levels of choice and control over their lives. The Fund has been efficiently run and, by and large, has been administered with a suitably light touch. Many service users' experience of using the ILF have been more positive than experiences with their local authority, particularly in relation to: the continuity of care management staff; the portability of the support package; and the clarity of policies and procedures.
- 3.5 As we have previously noted, we would have liked to see the resource maintained and expanded in Scotland rather than frozen or terminated. As the above comments illustrate, the ILF has enabled many disabled people to live a life that is not just about life and limb provision and mere survival. It has enabled people to participate fully in society and, indeed, to exercise their rights and responsibilities as equal citizens. In short it has enabled what we call 'independent living'.
- 3.6 Independent living means:
'...all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.'¹

What has not worked so well?

- 3.7 Criticisms of the ILF mainly centred on the eligibility criteria, the financial assessment, and the monitoring requirements.
- 3.8 Raising the eligibility threshold and then closing the ILF to new members has clearly been the biggest problem. This is now being aggravated by the disproportionate impact on disabled

¹ <http://www.ilis.co.uk/independent-living>

people of the welfare reform agenda and stricter local authority social care eligibility criteria combined with increasingly punitive charges (Care Tax).

- 3.9 Participants also felt that the eligibility criteria discriminated against people over sixty five. They also thought the financial assessment was unfair:

My pension is regarded as non-earned income; therefore I was asked for a personal contribution. My wages had been ignored when I was working.

When I was working they disregarded my earnings but as soon as I retired my pension was taken into account and I had to make a contribution. That was crazy as my income had dropped!

- 3.10 Some people felt the monitoring procedure was too onerous and too much paperwork was required at review to prove how the money had been spent: paperwork records needed to be kept for too long.
- 3.11 In addition to the above, GCIL would note the following shortcomings in the previous incarnation of the ILF.
- 3.12 Although, as an independent Trust, its policies have the merit of being influenced by disabled people through its governing body, funding is still provided on a charitable basis rather than as a right with transparent appeal mechanisms. This is not consistent with the view that independent living should be a civil and human right.
- 3.13 The ILF could also have responded better to the needs of those employing personal assistants to meet their various legal responsibilities under employment legislation, for example, in relation to redundancy payments.

Question 2: Should the money that becomes available after existing ILF recipients no longer need it be used in the same way for others in the future? If so, why? If not, how else might the money be used?

- 3.14 Various suggestions were made about how the money should be used. Priorities included maintaining existing packages, and allowing people to remain in their own homes so they could live their lives in the way they choose:

We need to keep people out of residential care - that should be a priority.

Sometimes the funding of appropriate equipment can reduce the hours of support needed.

- 3.15 Some people thought that money which becomes available should be used to provide new support packages.
- 3.16 One suggestion was that short term awards should be available for emergencies.

Question 3: If the available resource is simply that which is transferred from the Treasury, how would you like to see it used if it was not to be a continuation of the existing approach?

- 3.17 However it is used, people felt it was important that eligibility criteria should be transparent, national and applicable across all groups.

Funding should be the same no matter where you live...it should be based on need.

- 3.18 GCIL strongly believes that it would not be fair to reduce or terminate existing awards in order to fund other disabled with support needs. Many service users agreed:

Don't take money from existing packages to meet new demand – this would be robbing the poor to pay the poor.

Question 4: What innovative ways might there be for increasing the overall amount of money in the pot?

- 3.19 Many suggestions from participants focussed on the need for other statutory agencies to recognise the importance of independent living and make a fair contribution. For example Access to Work should fund the support people need at work,

not ILF as is sometimes the case at present. Others thought the NHS should make more of a contribution:

The NHS should contribute more to keeping people at home and healthy rather than waiting for a crisis to arise.

The NHS should contribute to a new ILF fund to keep people out of nursing care.

3.20 However, a number of people thought the Scottish Government should top up ILF funds to allow people to continue their current packages of support and also meet the needs of new people.

In addition to the money transferred from ILF, the Scottish Government should raise more money through taxation for social care.

People on the Extension Fund don't get local authority funding so need to be protected. I think we need a Scottish ILF.

3.21 Another suggestion was that local authorities could reduce waste, for example by sharing infrastructure and resources more.

3.22 GCIL supports the view that, given the significant additional resources which a more comprehensive Scottish solution based on independent living principles would require, we need to take a broader perspective on what we are aiming to achieve. Although social care plays a vital role for many disabled people in enabling independent living, we know that it is only a means to an end. Life is about more than just being clothed, fed and kept out of harm's way. Disabled people have identified around 15 areas of life – the so-called pillars of independent living – which are important if independent living is to be fully realised. These include:

- inclusive education and lifelong learning
- equal opportunities for employment and training for work
- full access to our environment
- fully accessible public transport

- technical aids and equipment
- accessible and adapted housing
- an income including income from benefits
- accessible and readily available information
- advocacy and working towards self-advocacy
- peer support, including from disabled people and their organisations
- accessible and inclusive healthcare provision
- appropriate communication support
- personal assistance and self directed support
- full social, civic and judicial participation
- legal rights

3.23 It could be argued that, from disabled people's perspective, there is an imbalance in the way society distributes resources across all these areas of life – not just in obvious areas such as health and employment. For example, even where public transport is accessible, some disabled people will not be able to make use of it without having support from a personal assistant. Similarly, being able to use educational, sporting or entertainment facilities may be dependent on access to sufficient social care.

3.24 We believe there is a compelling argument for drawing on the wide range of budgets which relate to these and other areas of life to supplement a Scottish resource capable of enabling disabled people to realise independent living.

Question 5: With any available resource, where is the most effective area to target resources which can have the biggest impact on an individual's ability to live more independently?

3.25 See responses to questions 2 & 3.

Question 6: Once funding has been devolved to the Scottish Government, which option do you think will be most appropriate for Scotland?

- 3.26 There was unanimous agreement that the funding should not be given to local authorities to administer. The main reasons included the fear that the money would not be ring-fenced and that, in the current financial climate, local authorities might use the money for purposes other than social care:

Everyone is faced with cuts just now, including local authorities, so the danger is the money would not be used in the way it was intended.

- 3.27 Participants also felt that a national scheme would be more cost effective and efficient to run. Others were concerned that flexibility would be lost as new, stricter, eligibility would apply which only tend to fund 'life and limb' support needs:

ILF allows you to have a life; it is more flexible than Local Authority funding.

The Local Authority would apply too strict a criteria, only washing and dressing etc.

Local Authority is less likely to fund overnight care for older people so I am afraid I would end up in care.

- 3.28 Some participants thought the Scottish Government should administer a Scottish version of the ILF:

The Scottish Government should manage the money to cut down on administration.

- 3.29 Suggestions regarding future administration of the money seemed in the main to favour the money going to the Third Sector. Many thought it should go to a user-led organisation to administer. Comments included:

The money should go to a new national board or trust to administer, preferably with user involvement.

Give the money to a consortium of voluntary organisations, mainly user-led.

The money should go to a national group that fully involves disabled people.

It should be managed by an independent disabled people's organisation.

3.30 GCIL would be opposed to the devolved funds being handed to local authorities. As outlined above, any transfer of funding from government to local authorities is likely to be swallowed up in local authority budgets without having a significant impact. In the longer term, the result will be more disabled people living in poverty and without the adequate support services they need to lead active lives as equal citizens. Indeed, the likely outcome is that more and more disabled people will be entering or returning to residential care purely on cost grounds. This would be a totally unacceptable return to the discredited practices of the past and utterly contrary to the empowering principles embodied by current SDS policy.

3.31 Although GCIL is not in a position to endorse any specific alternative delivery model we do believe that any solution should be underpinned by the following principles agreed by Disabled People's Organisations:

- **Overarching principles of independent living, equality and human rights:** The principles of independent living, equality and human rights should steer what happens – this includes promoting, protecting and supporting the full participation for all disabled people as equal engaged citizens.
- **Freedom:** users of community care are free to live their life in the way that they choose, without barriers to such freedom created by care and support systems, which are inflexible and operate to their own convenience.
- **Choice:** users of community care can choose how to live their life, what they do with it and who they involve in it.

- **Dignity:** everyone is entitled to dignity in their own life and others respect this dignity – from the point of accessing support to the delivery of it.
- **Control:** people can and should control their own lives, including what they do, with whom, and when they do it.
- **Participation:** disabled people have a right to participate in society and decisions which affect their human rights.
- **Accountability:** those responsible for the promotion and delivery of respect, protection and fulfilment of human rights are accountable to those who hold such rights.
- **Non-discrimination and equality:** Community care is crucial for the equality and human rights of disabled people. Without it, many disabled people cannot live free from discrimination and harassment as the Equality Act 2010 promotes, enjoy the human rights to which they are entitled on an equal basis to others – as set out in the Human Rights Act and the European Convention of Human Rights, nor contribute to a wealthier and fairer, smarter and healthier, safer and stronger, Scotland.²
- **Empowerment:** disabled people know their rights and how to claim them. They are supported to play an equal, engaging part in society and lead an ordinary life.
- **Legality:** decision makers must make an explicit link with human rights legal standards in all processes and outcome measurements.
- **Stability:** disabled people do not live in fear of losing their support or about the perception of others of the cost of such being not worthwhile. This includes; decisions and practice around funding levels, assessment, eligibility and review processes; as well as decisions around the continuation of

² ILiS; “ILiS Response to the JCHR Inquiry into the Implementation of Article 19 of the UNCRPD”, 2011

‘buying’ a consistently high service – either as ‘good employers’ or to retain a preferred agency/provider.

- **Better outcomes for individuals:** rules and processes, including assessments and eligibility criteria, work to the benefit of the individual and their best interests. The outcomes for disabled people and other users of community care, in terms of better health and wellbeing, should be at the centre of both the legislation and the way that it is implemented.
- **Portability:** Disabled people and other users of community care have clear entitlements to it, regardless of where they live. Disabled people know that they can move freely, for whatever reason, across Scotland and that their support package can come with them.

Question 7: To assist with our partial Equality Impact assessment in relation to the future development of a sustainable Fund to support disabled people in Scotland to live independently, please describe any equality issues (in relation to age, disability, sex, sexual orientation, gender re-assignment, race, religion or belief, pregnancy and maternity and marriage and civil partnership) that you feel may arise and suggest ways in which these could be addressed.

Clearly, the issue of equality is at the very heart of our arguments about the need for an effective source of practical assistance and additional support to enable independent living. Equally, the principles underpinning the eligibility criteria and delivery model will determine to what extent the chosen solution fulfils the Scottish Government’s duties to promote the equality of disabled people as set out in the Equality Act 2010.

It is important to remember that, ensuring equality of opportunity does not necessarily mean treating everyone the same. For example, disabled people may need additional resources just to equalise the dual income disadvantage they often experience as a result of having less income to start with, and having to pay more to achieve the

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same basic outcomes as non-disabled people eg getting up in the morning and ready for work. Without an adequate replacement for the ILF, inequality and poverty for disabled people will continue to rise.

More specifically, we believe that eligibility criteria should not reflect implied value judgements about 'deserving' and 'undeserving' groups. For example, we do not see any compelling reason to treat disabled people any differently who are older, not in paid employment, who have partners' with their own income and capital, or who have income from occupational pensions. Finally, we believe more targeted work is needed to ensure that disabled people experiencing multiple forms of discrimination, for example, disabled people from black and minority ethnic communities, get equal access to available support.

Etienne d'Aboville
Chief Executive
Glasgow Centre for Inclusive Living
117-127 Brook Street
Bridgeton
Glasgow
G40 3AP

Tel: 0141 550 4455
Textphone: 0141 554 6482
Fax: 0141 550 4858
Email: etienne@gcil.org.uk

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