

## CONSULTATION QUESTIONS

### SUMMARY;

In principle, I agree with the submission from Disabled People's Organisations (DPO) in Scotland:-

#### **Joint Statement from Disabled People's Organisations in Scotland:**

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 staff expertise in Scotland**

**Administer the funding nationally, through an independent trust**

However, as an individual responder, I should like to do some 'blue-sky' thinking

**First and foremost I repeat – and it does need repeating continuously – the need to guarantee on-going support to existing users which would meet any additional expenditure due to increasing personal need, provider fees, or employer duties.**

However, I make the argument that 'independent living' is a human right of disabled people, under Article 19 of the United Nations Convention of the Rights of People with Disabilities. The exercise of rights and responsibilities are part of citizenship and necessary for the full engagement of citizens within society at large.

If welfare and social services were designed around promoting and sustaining such exercise, rather than merely meeting the personal and social 'needs' as acknowledged and defined by professionals, there would be much more dynamic participation by disabled people within the community, leading to a much more progressive, inclusive and vibrant society.

Therefore, the use of any attrition, within an independent trust, and with any additional resource, should be used to overcome the structural barriers within society which prohibit independent living and the active participative engagement of equal citizenship by disabled people.

First, the money could be used to fund pilot projects within local authorities to provide community care support based on the principles of asset citizenship – the provision of assets to maximise engaged citizenship.<sup>1</sup> Therefore any new/additional money would begin by dismantling the structural barriers within social care which prioritises ‘limb and limb’ cases and provides minimal dependency creating services.

Although such small scale projects could be started without much policy debate or change, I do realise wider structural change in social work provision may require some kind of enquiry or commission. This would look into the current state of neoliberal managerial social work<sup>2</sup> which can only provide minimal support to a few who meet the strictest of ‘life and limb’ criteria.

However such an enquiry/commission could also consider other options of service objectives and delivery systems, including, possible ways such services could promote and support a system which values **engaged** proactive participative citizenship. I strongly believe there would be a more vibrant and inclusive society if it transferred its concern from the cost of social care to its value, not just to the users and their families, but to society as a whole.

But social care is only one area of structural barriers to disabled people’s independent living: independent living is not just about personal support. Disabled people have identified 13 areas of living and support (including, education, housing, transport, etc.) to which the policies and practices covered by the independent living paradigm can be applied.

It can be seen, therefore, that independent living touches on all aspects of life and much of government policy and expenditure. If the attrition of this new budget were to be enhanced with money (say 0.01%) top-sliced from each of the relevant budget headings, then along with the growing attrition, an alternative, if not additional, use of the new budget could be to fund projects which tackled the structural barriers within each of the 13 areas covered by the independent living paradigm.

I further suggest that the Scottish Government’s Independent Living Partnership Board could oversee the implementation of such structural programmes, run on the Scottish Government’s improvement model established in the health service and now being applied to children and families services.

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<sup>1</sup> The concept of the state providing assets to individuals to facilitate their citizenry participation was introduced by Thomas Paine in the 18<sup>th</sup> Century, in his book “Agrarian Justice”; but more recent discussions around a “stakeholder society” can be found in Ackerman, B, Alsott, A, and van Parjis, P, eds, (2006) “Redesigning distribution: Basic income and stakeholder grants as cornerstones for an egalitarian capitalism”, Verso, London

<sup>2</sup> Ferguson, I (2008) “Reclaiming Social Work: neo-liberalism and promoting social justice”, Sage, London

## Question 1

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

### **What worked well:**

My late wife had been in receipt of ILF funding from its inception in the late 1980's. However, it turned me down because it saw me as her carer. Nevertheless, since I was receiving more than £200 in indirect payments from my local authority, it ultimately accepted my application in 1993.

From those dates, it kept my wife at home and me in work. It allowed us to have a normal married life together until her death in 2012. It assisted us in our joint and separate activities. Those joint activities included participating in extended family life, holidaying and being part of local social and civic activities of our community. It also enabled my wife to obtain her third university degree, this time a first in mathematics. Since her hero was Professor Stephen Hawkins, who has a similar degree of impairment to hers, she was very proud of this achievement. Following my own enforced retirement on health grounds in 1999, the ILF has also enabled me to continue in my role as an equal citizen, volunteering for several organisations including those within the disabled people's movement.

But, alas, it will no longer do so after 2015; and my future not only in terms of being an equal participative citizen of Scotland, but having my own personal quality of life, is now in jeopardy

I say this because all of those outcomes noted above, made possible with ILF funding, would have been impossible, if we only received assistance from our local authority. Like most Scottish local authorities, it would have provided minimal dependency creating services to those in greatest need of 'life and limb' services.

Unlike the multiplicity of ideas and perceptions of 'independent living' which can be found among the thirty-two local authorities and their hundreds of individual politicians, policy officers, managers and assessment officers, the ILF has truly reflected disabled people's definition:

**"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."<sup>3</sup>

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<sup>3</sup> <http://www.ilis.co.uk/independent-living>

This is also the definition adopted by the Scottish Government, CoSLA and the Scottish NHS in a “Shared Vision Statement” with Disabled People’s Organisations in Scotland.<sup>4</sup>

As can be seen, this concept of independent living is couched within a framework not only of personal liberty, of being in control of one’s personal everyday life, but having the same rights and opportunities to ‘equal participative citizenship’ in society at large just like other non-disabled people.<sup>5</sup>

Such commitment as expressed in this Statement is due to the belief of all four parties that promoting independent living is the right thing to do, and it is in Scotland's interest to do so:

- It is right for the individual - to be free from prejudice and discrimination; and to participate within society as full, and active, equal citizens
- It is right for public bodies - putting this agenda at the heart of planning and service delivery will make them more effective and more efficient at targeting limited resources to needs, reducing spend in the longer term and meeting their legislative duties
- It is right for our economy - the more diverse the economy, the more innovative and high growth it is; and the more successful it will be at recognising, attracting and growing talent
- it is right for society as a whole - a more equal society will have greater strength and social cohesion<sup>6</sup>

Independent living policies, practices and procedures are therefore necessary for the full engagement of disabled people’s citizenship and underpinned by their human and civil rights.

Throughout the world, countries belonging to the United Nations have acknowledged that ‘independent living’ is a human right for disabled people, under Article 19 of the United Nations Convention of the Rights of Disabled People:

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<sup>4</sup> <http://www.scotland.gov.uk/Publications/2010/03/29164308/1>

<sup>5</sup> Morris, J (2005) “Citizenship and disabled people: a scoping paper prepared for the Disability Rights Commission”

<sup>6</sup> <http://www.scotland.gov.uk/Publications/2010/03/29164308/1>

## **“Article 19 – Living independently and being included in the community**

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”<sup>7</sup>

And the UK government is a signatory to this Convention

As well as helping disabled people, like myself, to be engaged proactive participative citizens, not just in the economic life of the community, but in its social, cultural and civic spheres, it should be acknowledged that the current ILF helps the Scottish Government and local authorities meet their Concordat and National Performance Framework.

It does this by assisting Scotland to become more inclusive in its attempt to be smarter, healthier, stronger and more equal. In particular it helps Scotland to “have strong, resilient and supportive communities where people take responsibility for their own actions and how they affect others” and to “take pride in a strong, fair and inclusive national identity”<sup>8</sup>.

Such high principled outcomes should not just be in the domain of the healthy and non-disabled citizenry. Disabled people and those with long term conditions should be given the assets, as I have been thanks to the ILF, to participate on an equal footing in such responsibilities. To deny them those assets and opportunities is to deny their right to full and equal citizenship<sup>9</sup>

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<sup>7</sup> <http://www.un.org/disabilities/convention/conventionfull.shtml>

<sup>8</sup> Scottish Concordat 2008-09 to 2010-11

<sup>9</sup> The concept of the state providing assets to individuals to facilitate their citizenry participation was introduced by Thomas Paine in the 18<sup>th</sup> Century, in his book “Agrarian Justice”; but more recent discussions around a “stakeholder society” can be found in Ackerman, B, Alsott, A, and van Parjis, P, eds, (2006) “Redesigning distribution: Basic income and stakeholder grants as cornerstones for an egalitarian capitalism”, Verso, London

The ILF is run as an independent Trust, which just lately has enabled disabled people to become part of its governing body. It is therefore accountable to its service users through policy design and practice. These principles should not be lost when the budget comes to Scotland.

The ILF has also accepted my view of my situation, without undue interrogation and questioning. Although this has also been true of my own local authority, friends living elsewhere in Scotland have told me of social work assessments which are reminiscent of the Spanish Inquisition. These were driven by the prominent neo-liberal managerialism of today's social work practice which places a market-driven agenda, before social work values and social justice.<sup>10</sup>

Using the scene from Shakespeare's play 'King Lear', when he is on hard times and pleads for help from his rich and powerful daughters, as an exemplar, the social philosopher Michael Ignatief states:

".... Human beings must be trusted to know themselves, however imperfect we admit self-knowledge to be, for without trust, there is no limit to oppression. If the powerful do not trust the reasons of the poor, these reasons will never be reason enough. A rich man never lacks for arguments to deny the poor his charity.

..... The demand to give reasons for need is the demand that the poor person, show themselves as deserving.

..... The claim of need has nothing to do with deserving; it rests on people's necessity, not on their merit; on their poor common humanity, not on their pathos.

..... Once the rich begin to demand reasons, once they cease to take claims on trust, Lear asks, what obligations will survive? Will the utterance of starvation be enough for the hard hearted? Why stop there? 'Man's life is cheap as beasts.'" <sup>11</sup>

I lose heart when I think that the UK government's ideologically driven neo-liberal welfare reforms, of which the closure of the ILF is a significant part, alongside the neo-liberalism of today's social work practice, could finally realise the fear of Shakespeare's King Lear – at least for disabled people – for it will make their lives as cheap as the beasts in the field.

The Scottish Government has shown how, despite the many restrictions in its path, it has tried to minimise the hurt and anguish such reforms have inflicted on its poorest and most vulnerable citizens. I would urge it to do the same for those who are now being put at severe risk by the closure of the ILF: not just those who are presently in receipt of the ILF but those who have been and will be excluded from its empowering and empathetic support.

<sup>10</sup> Ferguson, I (2008) "Reclaiming Social Work: neo-liberalism and promoting social justice", Sage, London

<sup>11</sup> Ignatief, M (1984) "The Needs of Strangers" Hogarth Press

Please do remember that the ILF was created by a Conservative government after a botched attempt to reform the welfare budget in 1987. It was disabled people themselves who campaigned against the ending of the personal assistance allowance within supplementary benefits, when 'income support' was introduced. It was disabled people who campaigned for their freedom from institutional segregation and the dominance of medical and social work practitioners over them and their life expectations. It was disabled people who promoted the concepts of independent living and self-directed support. It was disabled people who finally forced the Conservative Government to set up the ILF which has realised and supported such freedoms for a quarter of a century. But it is disabled people who fear the most that all of these humanitarian and civic rights advances will now be lost within this current Conservative led botch-up of the welfare state.

Despite its drawbacks and the fact that it leaves a bitter taste in many a mouth by being constituted as a charity, the ILF is very close to the hearts of many disabled people. It has given them the assets they need to fulfil their lives within the family, the labour market, cultural and social activities, peer friendships and civic duties – all of which constitute the engagement of their full and equal participative citizenship

But the fear of the 1980's still exists today; that many enabled to contribute in such manner to the socio-economic fabric of society at large due to the provision of their personal support will end up back in segregated institutional provision dominated by the socio-medical professions.

But apart from social, political and philosophical reasons for ensuring the concept and practice of independent living continues despite public sector neo-liberal managerialism, there are truly economic reasons as well.

There have been many studies showing the benefits both in cutting costs and improving quality of life due to independent living programmes and self-directed support. As one example only; a study has shown that every £1 spent on preventative and community services generates benefits to people, carers, local and central government worth an average of at least £1.30.<sup>12</sup>

In addition, the ILF has given many the continuity of the same care manager over a long period; the portability of a support package, which they can take anywhere in the country; and nationally accountable standards in eligibility criteria, staff practice and training, as well as fair and transparent policies and procedures, which, in many cases, have been consulted upon with the end user

I believe the ILF is an efficient, equitable and exemplar social care and support model. The initiative should continue and be opened up with new resources allocated to it, in Scotland.

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<sup>12</sup> <http://www.scope.org.uk/news/massive-economic-benefits-providing-social-care-disabled-people>

## What has not worked well:

In my own experience the worst aspect of the ILF has been its tardiness to acknowledge my duties and responsibilities as an employer. Resources (money) were provided to meet need, with a nod to the requirement to pay monthly taxes to the Inland Revenue. However, on the death of my wife, as an employer it was my duty to pay off three of our part-time employees. I had to do this within the confines of employment law; interviewing everyone and working out the intricate and accumulative parts of redundancy moneys, which I was expected to provide to those losing their jobs.

Unfortunately, there was no immediate response from the ILF to meet these large amounts of money. This was surprising, because as recipients were only allowed to have an additional two weeks funding above their four weekly payments in their account books, I had expected some procedure to be at hand for large unexpected expenditure, such as redundancies.

At a time of grief and relative vulnerability I was exposed to a situation where I was in danger of being taken to an industrial tribunal by three angry ex-employees and no assistance to meet the redundancy moneys they were demanding.

Fortunately, although they could not give me the money, I did have the moral support of a user-led Centre for Inclusive Living. Such peer support is invaluable to disabled people; yet it is so under-valued by present day neoliberal managerial social work practice and procedure.<sup>13</sup>

Arguments have been made in academic journals that independent living and self-directed support reconceptualises work and welfare:

“... to run direct payment type schemes users must build on or acquire particular skills in order to recruit, manage and supervise PAs. ... This involves the development of a range of transferable skills such as recruitment, interviewing, management, accounting, supervisory and interpersonal skills that, in any other environment would be classified as work.”<sup>14</sup>

However, such academic discourse has not impinged upon practical policy and practice in delivering self-directed support provision. I find it regrettable that ILF policy and procedures are mainly hewn in the light of their ‘customer’ being a ‘needy’

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<sup>13</sup> As an aside, in view of the demise of so many peer support organisations, due to lack of funding, I regret questions around the precarious situation of peer support organisations which give so much added value to helping disabled people manage their self-directed support systems, are not in the frame. This may be because they are being discussed elsewhere, i.e. within the self-directed support arena. However, I would suggest some overview be taken of both self-directed support and this new budget, in whatever form it may take.

<sup>14</sup> Prideaux, S, Roulstone, A, Harris, J and Barnes, C (2009) “Disabled people and self-directed support schemes: reconceptualising work and welfare in the 21<sup>st</sup> century”, *Disability and Society*,24:5, 557-569

and 'dependent' welfare recipient, rather than an empowered employer in the labour market or a proactive consumer in the social care market

A fundamental issue with the ILF has been the milieu and foundation of its growth. It was conceived and developed within the framework of basic income support and the concepts of such provision. Eligibility and charging criteria have been dominated by income support regulations and practices. This has led to institutional repression and enforced poverty among its recipients, denying them social mobility and the freedom to save for the future welfare of their children, a holiday or house refurbishment and repair, etc. etc...

If the ILF were based on the true concepts of equal citizenship engagement and the promotion of a participative stakeholding society, then the eligibility and charging regime bars should be much higher than those based on income support rules and criteria. Disabled people have been paying too much too long for their inherent rights as human beings and civic rights as equal citizens.

I have been in the position, fortunate or otherwise, of seeing the ILF change from being a keen ally of disabled people's empowerment and emancipation to a very reluctant one. Politicians of all colours have criticised its diligence and passion to support disabled people as equal citizens. Successive governments have curtailed its endeavours by raising eligibility thresholds, reducing contingency moneys, closing it to new members. Now, the coalition government is closing it altogether. This death by a thousand cuts has been aggravated by the disproportionate impact of the welfare reform agenda. Regrettably, this entire aggressive onslaught on the well-being and brio of disabled people has had a very negative and hurtful outcome on their lives, resulting in some committing suicide.<sup>15</sup>

## 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?**

I do appreciate the stance taken by the Scottish DPOs in calling for any new fund to be open to new recipients. The decision by the UK Government to close the ILF to new recipients did create a massive amount of unmet need; and the complete closure will further exacerbate inequalities between disabled and non-disabled people in the future. These inequalities are not helped by local authorities only providing support packages with basic cover<sup>16</sup>; or by the UK Government's targeting of disabled people in the welfare agenda creating even further poverty<sup>17</sup>.

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<sup>15</sup> See <http://atosvictimsgroup.co.uk/tag/suicide/>, <http://www.independent.co.uk/voices/comment/enough-is-enough-disabled-people-are-driven-to-suicide-because-of-the-governments-welfare-reform-8197640.html>, <http://www.newstatesman.com/blogs/politics/2012/07/welfare-reform-suicides-must-not-be-overlooked>, <http://www.bbc.co.uk/news/uk-scotland-scotland-politics-15839685> and <http://calumslislist.org/>

<sup>16</sup> <http://www.scope.org.uk/news/other-care-crisis> and <http://www.inclusionsscotland.org/documents/FiveAsks.doc>

<sup>17</sup> <http://www.inclusionsscotland.org/news/story.asp?id=4181>

And as an existing recipient of ILF, I do agree that any new use of existing money should not come from the funding of existing support packages. These funded packages should not only be secured, but under-written by guarantees that additional resources will be available for any additional increases in costs of meeting the increasing personal need, providers' fees, or employers' responsibilities of existing clients. Such increases in personal budgets should come either from the attrition within the existing budget or from other Scottish Government budgets.

I do not say this for selfish reasons, but for deontological and ethical ones. It has been argued that society has a duty of beneficence and non-maleficence, as well as care and justice, especially to those who are not as strong and resilient as others.<sup>18</sup>

It is also morally wrong to take from Peter to give to Paul, especially if both are within a protected group within equality legislation and both are seen as being 'in need' within current community care legislation. It is not ethically comfortable to think that the state redistributes resources to the disabled people from disabled people, when they have a duty to equate their status and opportunities with non-disabled people

I am truly grateful to the Scottish Government for accepting this principled stance, but would urge it to resist any pressure from any quarter to change from it

However, personally, I should like to take this opportunity, as an individual to do some 'blue sky' thinking on the issue of what to do with the attrition within any 'new' independent living budget when it comes to Scotland, or if there were any initiatives to spend the money differently.

I do realise that such thinking may be impossible to realise, given the current political thinking which dominates society's attitude and actions in the light of 'austerity Britain'. It may also necessitate some kind of enquiry or commission into the state of neoliberal managerial social work and the possible ways such services could promote and support a system which values proactive participative citizenship. And there is the obvious disadvantage that such an enquiry/commission may push the issue into the 'long-grass'. Nevertheless, I strongly believe there would be a more vibrant and inclusive society if it transferred its concern from the cost of social care to its value, not just to the users and their families, but to society as a whole.

However, I do hope that I will drop some seeds for thought, which might gestate over a period of time and eventually flower as time goes by: and I am personally convinced that the transfer of the ILF budget to Scotland could accelerate that process.

In doing such 'blue sky' thinking, I would also like to give a combined answer to:

### **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?**

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<sup>18</sup> Darwall, S (ed.) (2003) "Deontology" Blackwell Publishing, London

#### Question 4

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

**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?**

And

#### Question 6

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

I do agree with the DPO submission that given the vagaries of what James Madison, 4<sup>th</sup> President of the USA, termed 'the tyranny of the majority', the most secure option cited by the consultation paper is a "New Partnership and/or Trust" (Option 4). Giving the budget to local authorities would not guarantee that it would be spent on community care. It could end up filling pot-holes, or paying for some feast-day. Even if it were added to local authority community care provision, it would only provide more fuel to the furnace of the neoliberal managerialism of present day social work, continue the post code lottery of provision, along with the exclusion of the voice/influence of the end user, who constitutes the minority in local authority elective decision-making, but 100% of the recipients of its service provision.

A new Partnership/Trust would give more security to existing recipients and tick the advantages described within the consultation document. If it also worked in co-production with disabled people<sup>19</sup>, it would overcome the issues discussed in the previous paragraph. It would also safe-guard the current aspects of the ILF which are important for the future of any funding:

- The money remains ring fenced to provide care and support and that the current level of 97p of every £1 spent reaches the end user
- It is delivered on a national eligibility criteria focussed on supporting and delivering independent living. The national consistency of the application of ILF moneys means that the provision is not subject to a post code lottery and it offers portability of support. This is crucial for disabled people to enjoy their freedom of movement around the country for their employment prospects, or to be near family, etc., without having to re-negotiate their funding
- It is portable and flexible

<sup>19</sup> <http://www.ilis.co.uk/get-active/publications/co-production-toolkit>

- It is provided after a co-produced assessment with the end user and with someone who is not the budget holder; therefore, ensuring decisions to offer funding are based on need, not on budget
- It is provided after a regular review to ensure needs are met appropriately
- It is provided as a Direct Payment. The ILF has shown a pioneering history and wealth of experience in delivering Direct Payments since the 1980's/1990's. This method of support has supported choice, control, freedom and dignity in the lives of disabled people in a way that more traditional care and support have been unable to offer
- It is monitored in a way that supports accountability whilst being flexible and non-intrusive

I also agree with my DPO colleagues, that the following principles be used to develop any successor system for the ILF in Scotland:

- **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.<sup>20</sup>
- **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 ‘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.

However, I am concerned that a new Trust would continue the bifurcation of social care.

The majority of social care will continue to be in the control of the present-day neoliberal managerial policies and practices, including notions of budget driven services, single-assessments, markets, competition, productivity, resource allocation systems, etc.; all of which limit positive outcomes, and merely for those few who meet the highly restrictive ‘life and limb’ criteria of the assessment process. Thereby, they are confined to dependency, segregation (even within their own home) and denial of their full and equal participative citizenship. I daresay that some will

<sup>20</sup> ILiS; “ILiS Response to the JCHR Inquiry into the Implementation of Article 19 of the UNCRPD”, 2011

claim this is a misrepresentation of social care practice, but such has been well documented in the literature<sup>21</sup>

On the other hand if the new fund meets the criteria which drive the existing ILF and which are detailed in the box above, there will be another system of social care which although not strictly based on the human rights agenda, nonetheless enables its recipients to fulfil more ably their familial, cultural, social, civic and economic lifestyles. This system is and could be more directly inclusive of the recipient in its policies, practices and assessments; and sees the recipient as an equal, participating and engaged citizen

Therefore, I would suggest that any new Partnership / Trust be set up on a long-term, but changing, basis; primarily to secure the continuation of support to existing recipients, but also to stimulate change within mainline services. Any attrition, along with any additional money (possibly from the new combined budgets of health and social care) would be used to set up pilot schemes within local authorities to carry out similar packages of support, based on the same criteria and management systems of the new Trust, the principles and actions of which have been outlined above.

The expectation is that these projects work like immunisation programmes within health, changing the metabolism not just within the body of the individual, but in the culture and systems of the organisation itself. Thereby, they will promote different outcomes again not just of the Trust's programme, but those it purports to serve. Unlike health, there is little money spent on preventative exercises within social care.

The Scottish NHS, this year, spent £17m in flu immunisation alone. This is above that spent on its child immunisation programmes. Such preventative measures save greater harm to the individual and greater expenditure to the health service when large scale epidemics arise. If such preventive measures were applied to social care budgets, the consequences of 'unmet need', and the additional expenditure to meet them, would be less, when they are finally acknowledged as severe 'life and limb' cases.

It is generally agreed that there is a widening gap within social care, not only in Scotland, but around Europe, between rising need and falling expenditure.<sup>22</sup> If that falling expenditure continues merely to meet 'life and limb' need that gap will never narrow. Health and wellbeing has been found to be greater among those who are empowered to participate in the lives of their community and within relationships.<sup>23</sup> It has been found, for example, overcoming the isolation of being housebound, leads to improved health and wellbeing outcomes. Starting up small scale projects to maximise social and civic intercourse would help in such preventative measures.

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<sup>21</sup> See, Harlow, E, Berg E, Barry J and Chandler, J (2013) "Neoliberalism, managerialism and the reconfiguration of social work in Sweden and the UK", *Organisation*, vol. 2, no 4, pp534-550; Ferguson, I and Woodward, R (2009) "Radical social work in practice: making a difference", Policy Press, Bristol; Regowski, S (2013) "Critical social work with children and families: theory, context and practice", Policy Press, Bristol

<sup>22</sup> Tarricone, R and Tsouros, A D (2008) (ed) "Home care in Europe: the solid facts" WHO, Univerita Commerciale Luigi Bacconi

<sup>23</sup> Wallerstein, N (1992) "Powerlessness, Empowerment, and Health: Implications for Health Promotion Programs". *American Journal of Health Promotion*, Vol. 6, No. 3, pp. 197-205

Adopting this ‘improvement model’<sup>24</sup> i.e. starting small pilot projects and building on their learning will facilitate the closure of this gap. The theory and practice of the improvement model, is well known to the Scottish Government and has been widely used in the organisation of its health service.<sup>25</sup> It is also being used with some relative success by local authorities within the roll out of their Change Fund for older people.

As the Scottish Government has an Independent Living Partnership Board, this could be used to oversee and facilitate such a programme of improvement pilots, facilitating solutions to any initial problems and ensuring the pilots meet and sustain their initial objects; criteria which the present Change Fund has not always been able to maintain. As these pilots grow in number and geographic spread, they should influence local attitudes and practices within social care, presently dominated by neoliberal managerialism

It should also be noted the Scottish Government’s Christy Report<sup>26</sup> on the future delivery of public services identified four key principles that should underpin future reform:

- Reforms must aim to empower individuals and communities receiving public services by involving them in the design and delivery of the services they use.
- Public service providers must be required to work much more closely in partnership, to integrate service provision and thus improve the outcomes they achieve.
- We must prioritise expenditure on public services which prevent negative outcomes from arising.
- And our whole system of public services - public, third and private sectors – must become more efficient by reducing duplication and sharing services wherever possible.

The pursuit of asset based citizenship and welfare would, I believe meet these fundamental principles.

But perhaps I could push the boat out a little bit further, in my ‘blue sky’ thinking, in a more ambitious attempt to overcome the social and structural barriers of society at large, which inhibit disabled people’s equal and full citizenship.

But first, it should be acknowledged, as stated above that ‘independent living’ is a human right for disabled people, under Article 19 of the United Nations Convention

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<sup>24</sup> Langley, G J, Moen, R, Nolan, K M, Nolan, T W, Norman, C L and Provost, L P (2009) “The Improvement Guide: a practical approach to improving organisational performance”, Jossey Bass, San Francisco

<sup>25</sup> <http://www.scottishpatientsafetyprogramme.scot.nhs.uk/docs/usingthemodelforimprovement.pdf>

<sup>26</sup> <http://www.scotland.gov.uk/About/Review/publicservicescommission>.

of the Rights of People with Disabilities. The exercise of rights and responsibilities are part of an engaged citizenship. If social services were designed around promoting and sustaining such exercise, rather than ‘needs’ as acknowledged and assessed by gate-keeping professionals, there would be much more dynamic participation by disabled people within the community, leading to a much more progressive, inclusive and engaged society.

As referred to earlier, one of the major benefits of the present ILF has been the enabling of disabled people to fulfil the pluralistic aspects of their citizenship. Equal participative citizenship is the key objective of disabled people’s independent living movement.

The development of the disabled people’s movement and its relationship to the various models of citizenship has been outlined in several works.<sup>27</sup> However, I just want to mention one – that of a stakeholding citizenry – for that type of social service, which supports the rights and responsibilities of an engaged citizenship, would underpin such a society. Giving disabled people a direct payment is a concrete example of developing an asset based stakeholding citizenry. If such pilot schemes were to be based on such concepts, this would revolutionize social care in Scotland, and overcome a large structural barrier to disabled people’s independent living opportunities.

As far back as the 18<sup>th</sup> century the idea of giving citizens assets (money) to develop their active participation as equal responsible citizens in the government and wellbeing of society has entertained much debate. The idea is to build on the assets each and every individual has by giving them money, and for them to decide how to use it to assist their contribution to, or engagement with, society. It could be to buy tools for a job, or pay for a course to improve their education. Such money would be recouped through inheritance tax.<sup>28</sup>

Two competing arguments are made in this discussion. First is the libertarian argument that if people ‘stake-blew’, i.e. frizzled the money away, they were free to do so. The republican argument is that such assets, money, should only be used to promote the engagement of the individual with society; and to ensure such engagement took place, there should be a light handed monitoring of such assets, for detailed policing of such would be impossible.<sup>29</sup>

These arguments around the use and misuse of such money have been going on ever since Thomas Paine first suggested asset based citizenship in 1795; and have also dominated the field of self-directed support, since its inception.

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<sup>27</sup> See, for example, Beckett, A E (2012) “Citizenship and vulnerability: disability and issues of social and political engagement”, Palgrave MacMillan, Basingstoke

<sup>28</sup> Prabhakar, R (2008) “Assets and citizenship” in White, S and Leighton, D (eds) (2008) “Building a citizen society: the emerging politics of republican democracy”, Lawrence and Wishart, London

<sup>29</sup> White, S (2008) “The emerging politics of republican democracy”, in White, S and Leighton, D (eds) (2008) “Building a citizen society: the emerging politics of republican democracy”, Lawrence and Wishart, London

The republican argument is based on a set of principles of democracy, very similar to communitarian thinking and that advocated by the independent living movement in Scotland.<sup>30</sup>

These are; the common good, independence, inclusion, deliberative decision-making, participation and economic egalitarianism. If we are to develop a stakeholding society supported by social services and the welfare state, then these principles must be intrinsic to their policy and practice.

The independent living movement has been in the vanguard of promoting these principles. In particular, the idea of a direct payment to pay for support can be seen as an asset provision to enable participation in, and engagement with, society. The independent living movement also encourages inclusion, participation and deliberative decision-making. It has advanced the concept of 'co-production' and published a 'Toolkit for co-production' which explains in plain language how disabled people can participate in policy and practice decision-making.<sup>31</sup>

Asset based welfare to promote engaged citizenship has been discussed in both America and Europe.<sup>32</sup> This should not be confused with "workfare" programmes devised in America and presently being replicated within the current Con-Lib welfare reforms, for 'engagement' means more than just participating in the labour market.

Within Britain, the idea of giving assets to people to empower their reciprocal role as citizen has been trialled by the last Labour government in the development of its Child Trust Fund. Each child was to be given £250 at birth, followed by another £250 at age seven. This money was to be invested in a Trust which would attract interest and growth in the stock-market over time. Families were also allowed to contribute to their children's Trust which would mature at age eighteen. The libertarian concept of the child being free to do whatever she wished was assumed, although politicians hoped the accrued money would go towards her further education

It is true to say that within Britain, asset-based welfare has been discussed mainly around helping the poor to save money. But in America, Scandinavia and others parts of Europe, asset-based welfare has a wider remit in engaging mainly 'the poor' to be engaged in their citizenship development and favours the uptake of education and employment opportunities.<sup>33</sup>

It would make sense therefore, if we are to change welfare and social services to be an asset creator for an engaged, participating citizenship to start with policies and practices around independent living. A direct payment to enable a disabled person

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<sup>30</sup> Elder-Woodward, J (2013) "Independent living: the frontier to communitarian welfare", Disability and Society, vol 28, issue 2

<sup>31</sup> <http://www.ilis.co.uk/get-active/publications/co-production-toolkit>

<sup>32</sup> Sherraden, M (1991) "Assets and the poor; a new American welfare policy", M E Sharpe Inc.; Le Grand, Julian (2013) "Subsidiarity and individual responsibility: quasi-markets and asset-based welfare". In: Brugnoli, Alberto and Colombo, Alessandro, (eds.) Government, governance and welfare reform: structural changes and subsidiarity in Italy and Britain. Edward Elgar, Cheltenham,

<sup>33</sup> Emerson, C and Wakefield M (2001) "The Saving Gateway and Child Trust Fund: is asset-based welfare, 'well fair'" The Institute of Fiscal Studies, London

not just to get washed and dressed, but to become active in her family, cultural, economic and civic life, is truly an asset-based welfare provision. However, it should be remembered that, although realised programmes of ‘asset based citizenship’ mainly started within programmes for ‘the poor’, the original concept was that it would be a ‘universal’ provision. However, it is considered that some may require more assets than other to achieve the same things.

For example, the Nobel Prize Winning Professor Amartya Sen, with his PhD student Wiebwe Kuklys, found that when ‘conversion handicap’ (those assets which are needed by disabled people to achieve the same things as non-disabled people) was added to ‘income handicap’ (that which is the difference in income between disabled and non-disabled people) the difference in the poverty gap between the non-disabled poor and the disabled poor rises from five to thirty percentage points.

As stated above, as disabled people need more assets (money) to achieve the same as non-disabled, it may be sensible to start asset based welfare with this group of people<sup>34</sup>

Referring to asset provision and ‘republican democracy’, the principles of which are stated above, White (2008) states:

“The vision is not of a utopia, of a society which fully realises the values of liberty, equality and ‘fraternity’, which have historically inspired progressive politics. But it is an ambitious vision nevertheless. It pictures an active state working to disperse property and increase the accountability of decision-makers throughout society. At the same time, as part of the process of dispersing power and enhancing accountability, the nature of the state itself is transformed by greater citizen participation in and around policy-making. We should not want a state that swallows up society, but nor should we reconcile ourselves to the neo-conservative vision of a market society (in which the market swallows up the society). The challenge is to put the state and the market in their place so as to build what we may call a citizen society.”<sup>35</sup>

But social care is only one area of structural barriers to disabled people’s independent living: independent living is not just about personal support. Disabled people have identified 13 areas of living and support to which the policies and practices covered by the independent living paradigm can be applied.

These include:

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<sup>34</sup> Kuklys, W (2005) “Amartya Sen’s capability approach; theoretical insights and empirical applications” Springer, Berlin

<sup>35</sup> White, S and Leighton, D (eds) (2008) “Building a citizen society: the emerging politics of republican democracy”, Lawrence and Wishart, London

- inclusive education and training
- equal opportunities for employment
- 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
- counselling, including peer counseling
- accessible and inclusive healthcare provision
- communication and appropriate support for communication
- personal assistance

It can be seen how independent living touches on all aspects of life and much of government policy and expenditure. If the attrition of this new budget were to be enhanced with a tiny sum (say 0.01%) from each of the relevant budget headings, then along with the growing attrition, an alternative, if not additional, use of the new budget could be to fund programmes or projects which tackled the structural barriers within each of the 13 areas covered by the independent living paradigm, as itemised above. Such funded projects would be based on the principles and practices of ‘co-production’ as detailed within the Scottish Independent Living Movement (comprised of DPOs in Scotland).<sup>36</sup>

Once more, the Scottish Government’s Independent Living Partnership Board, which already works to the principles and practices of co-production, could oversee the implementation of such structural programmes, run on the Scottish Government’s improvement model established in the health service and now being applied to children and families services.

**Of course, never forgetting, there would still be a need to guarantee on-going support to existing users which would meet any additional expenditure due to increasing personal need or employer duty.**

### 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.**

<sup>36</sup> <http://www.ilis.co.uk/get-active/publications/co-production-toolkit>

I have no comment on this other than to reiterate the deontological and ethical reasons for not taking from one subset of a protected group, under equality legislation, to meet the needs of another subset. The purpose of equality legislation is to equal the welfare and economic opportunities of the entire protected group with that of the non-protected group, not further oppress them by thinly spreading out under resourced assets.

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