

P-05-771 Reconsider the closure of the Welsh Independent Living Grant and support disabled people to live independently – Correspondence from the Petitioner to the Committee, 28.09.17

Dear Mr Rowlands

Many thanks for accepting my petition at the Senedd on September 20 and for taking the time to listen to my concerns regarding the closure of the Welsh Independent Living Grant (WILG). I also appreciate the right to reply to the letter regarding my petition written by Rebecca Evans AM.

As outlined in my petition, the Welsh Government put WILG in place with local authorities to enable them to maintain payments to recipients in Wales of the Independent Living Fund (ILF). This was following the closure at that time of the ILF by the UK Government in 2015. The Grant was introduced to ensure continuity of support in the short-term for recipients.

This move did help Local Authorities to support individuals to meet the additional costs of living independently in the community in a similar manner to the financial support they received from the ILF. However, it has not allowed for any increased payments to cover any change in circumstances, a particular problem for those of us with progressive conditions. I had faith that the Welsh Government would resolve this issue after holding a consultation into how best to provide support to recipients in the longer-term, so as continue our ability to live independently.

A stakeholder advisory group was established that included a number of my contacts as well as representatives from local authorities. The advisory group considered a number of potential options to provide support in future to those who used to receive payments from the ILF. These ranged from perpetuating the WILG indefinitely, or for a set period of time, to establishing similar arrangements in Wales to that of the ILF outside of local authorities' provision [option 4] to having support provided in future through local authorities' social care. The advisory group considered the advantages and disadvantages of each option in terms of its effectiveness to support former recipients and its fit with supporting the larger

group of disabled people in Wales who had been excluded by the UK Government from receiving support from the ILF (as it had in 2009 closed the ILF to new entrants).

I have a real problem with the assertion from the Minister that the stakeholder group were united in agreement with the closure of WILG and the transferring of funds to local authorities. This was quite simply not the case and I request that she provides evidence in support of her claim that "the advisory group on balance favoured the option of future support being provided by local authorities as part of their social care provision. None of the members of the advisory group opposed this recommendation." For instance, was a vote held in the stakeholder advisory group? If so, on what date, what was the result, and can the minutes of that meeting please be provided?

I have spoken to several members of the advisory group who DID oppose LA provision. Surely, this calls into question the basis for the Minister's decision. There's been a total lack of imagination on the part of the Welsh government in terms of creating an independent living plan that all local authorities must buy into. This would be a guarantee of ensuring equity across Wales.

However, this option [option 4] was not given a fair hearing during the stakeholder sessions despite its popularity across Wales when all options were put out for consultation. We were unforgivably never given the result of this consultation, and it seems churlish for the Minister to say that many people – with high care and support needs and lack of empowerment – did not reply. The percentage of voters in general elections has been disappointing for many years, but that does not make our political representatives invalid. I would also challenge the Minister to release the data collected in the consultation.

The members of the stakeholder group that I have spoken to have stated their frustrations with the whole process: "I disagreed with one side of the room almost continuously," and "I would be amazed to see minutes of a meeting where all participants agreed that passing this WILG over to the local authority beyond the ring-fenced period was the way forward." Others have said "I used to go home from all these stakeholder groups thinking we had agreed certain things to discover that was not what had been recorded." and other activists argue that many officials and civil servants do not actually "know what Independent Living means – they still think 'independent' means managing without support".

It would greatly assist me in understanding Welsh Government's decision making process on this issue if the minutes of all of the meetings of the stakeholder advisory group can be provided, and I will submit a Freedom of Information Act request if necessary.

The short-sightedness of the Welsh Government is also highlighted by developments in Northern Ireland where they have recently decided to use the ILF model to support all community living for disabled people.

I would like to ask the Petitions Committee to ask the Minister to provide a copy of the Equalities Impact Assessment (EqIA) on which the policy decision was based. If the Minister cannot show a genuine and thorough EqIA then I would have thought the policy change has little legal standing. A former member of the stakeholder group recalls that: "at one stage there was a jump from all options being on the table (including a Welsh ILF) to "this is what's been decided", without an EqIA being carried out."

I think that the future of Independent Living in Wales depends on a robust enforcement of the Social Services & Wellbeing (Wales) Act. If local authorities make genuine efforts to empower individuals to identify and achieve their Personal Wellbeing Outcomes and access all aspects of Independent Living as a civil and human right that would be great. However, I am not holding my breath. The SSWb Act was promoted by officials as "a guaranteed enforceable right to independent living". This is all positive stuff on paper, but unfortunately disabled people do not live on paper and in the real world we need to see a tough enforcement of this Act. While we wait for this to happen - I do not expect it to be truly functional in my lifetime - we need a necessary protection for those with high care and support needs such as WILG. I would therefore ask the Minister to delay ending WILG until she has concrete evidence that all 22 authorities are genuinely supporting people to achieve their identified wellbeing outcomes. A Stakeholder Group to look at this would be a transparent means to allay people's genuine fears.

One very practical way for Welsh Government to respond to the UN Disability Committee's concerns about disabled people's rights in the UK is to reconsider its misguided policy on supporting former ILF recipients. For more information, please refer to the following link:

<https://assemblyinbrief.wordpress.com/2017/09/19/rights-of-disabled-people-how-the-un-committees-findings-relate-to-wales/>

I understand that Welsh Government's Framework for Action on Independent Living is currently being reviewed. I very much hope that the Framework will be strengthened as a result and that in particular, the rights of former ILF recipients will be supported by Welsh Government re-convening the

stakeholder advisory group to reconsider its WILG policy.

Finally, I would like to draw your attention to the situation in England following the closure of ILF in 2015 when money was transferred to Local Authorities in the same manner that is being proposed by the Welsh Government. This cannot be allowed to happen in Wales. A report by the Department for Work and Pensions (DWP) shows that former recipients of the ILF in England experienced a loss of support, a greater reliance on unpaid care and an “adverse” impact on their physical and mental health after its closure. All of these concerns were raised by disabled activists who campaigned against the decision to close the fund, before it shut in June 2015.

Those former recipients who saw their support “heavily reduced” as a result of the closure –which saw non–ring–fenced funding passed by the government to local authorities – “experienced multiple changes” to their lives.

The report says: “They argued that reductions in care were unfair and denied them opportunities to participate fully in society.

“They encountered changes and restrictions to daily activities, including less support for engaging in leisure activities, work and volunteering.”

Some of those who took part in the DWP study said that the “heavy reduction in care” they had experienced had damaged their physical and mental health, with effects such as loneliness, weight loss, and frailty “due to worry, or due to the physical demands of having to perform everyday activities without the support of a carer”.

I have also included three links at the bottom of this letter that will lead you to further information and reports on the dire situation that disabled people find themselves living with in 21st Century England. This is hardly in keeping with the Welsh Government’s landmark SSWb Act.

I could go on and on all evening about the problems that the closure of WILG will present to disabled people and their families. I haven’t even mentioned the impact it will have on support workers who rely on WILG for their income. As an employer, I do not want to have to tell my team of personal assistants that I will no longer be able to employ them.

In May 2015, I was told by my Local Authority, that without the protection of WILG my hours of care and support could be reduced from 86.5 hours a week – totally inadequate for someone with a rapidly progressive disease – to only 31 hours per week. As an active member of the community, this

would cause isolation and depression. I have no interest in merely existing. I want to live my life like everybody else and I feel that I have become an integral part of my community through involvement with Disability Wales, the Care and Social Services Inspectorate for Wales, Glyndwr University, Wrexham AFC and FDF Centre for Independent Living. This is not to mention my work as an author and poet while I have also been awarded an Honorary Fellowship from Glyndwr University for my work in Disability Rights. To have my hours reduced so drastically – as threatened by my social worker – would have a devastating impact to me and others.

I wish I could write more but time is at a premium. I look forward to hearing the outcome of the petition committee's discussions and have faith that the National Assembly will not turn their backs on disabled people with high care and support needs.

Should you need any further information please do not hesitate to get in touch using my contact details above.

Yours sincerely

Nathan Lee

Davies

Please find below links to three different reports into the effects of the ILF closure in England:

<https://www.gov.uk/government/publications/independent-living-fund-post-closure-review>

<https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/independent-living-social-care-and-health/ilf-one-year-on/>

<https://www.disabilitynewsservice.com/independent-living-fund-shocking-drop-in-support-after-ilf-closure/>

In addition, I have added some links below concerning my own fight for the continuation of WILG:

<http://www.leaderlive.co.uk/news/2015/07/07/gallery/our-fight-to-fund-independent-lives-in-flintshire-and-wrexham-74959/#.VZu96zMTWf4.twitter>

<http://www.disabilitynewsservice.com/welsh-government-has-sold-disabled-people-down-the-river-on-post-ilf-plans/>

[http://www.bbc.co.uk/news/uk-wales-politics-](http://www.bbc.co.uk/news/uk-wales-politics-38385381?SThisFB)

[38385381?SThisFB](http://www.bbc.co.uk/news/uk-wales-politics-38385381?SThisFB)

[https://nathanleedavies.wordpress.com/save-wilg-](https://nathanleedavies.wordpress.com/save-wilg-campaign/)

[campaign/](https://nathanleedavies.wordpress.com/save-wilg-campaign/)

<https://www.disabilitynewsservice.com/disabled-activist-is-fighting-for-his-life-as-he-hands-petition-to-welsh-government/>