

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, 16.10.18

<https://nathanleedavies.wordpress.com/>

Eich cyf/Your ref Petition P-05-771

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Chair
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16th September 2018

Dear Mr Rowlands,

I would like to begin by thanking you and all the members of the Petitions Committee for your work in collecting responses from other parties in relation to the planned closure of the Welsh Independent Living Grant.

The responses that I have read are all critical – to some extent – of the Welsh Governments handling of the closure of WILG. Other recipients and their families agree with #SaveWILG campaigners that this grant must be saved. Surely it is only right to listen to those that will be affected?

The responses from Conwy and Torfaen Council both argue that the end of WILG can be seen as a positive that will streamline an unfair two-tiered system. As you can imagine, I strongly disagree with this and have submitted over 100 pages of evidence to the committee over the past 12 months to support my opinions.

- WILG recipients all have high care and support needs. They rely on the tripartite system of support as without this they are solely reliant on Local Authorities and left without support should they experience any problems with their care and support. The consequences of so-called streamlining are deeply concerning as disabled people do not wish to be reliant on cash strapped local authorities. Indeed, during the consultation process disabled people and their families agreed wholeheartedly that it would be better to receive less hours of support while maintaining the tripartite system rather

than relying on Local Authorities and putting all their eggs in one hole–ridden basket.

- To address concerns of a two-tiered system, surely it would be fairer on everyone to open up WILG to ALL disabled people with high care and support needs.
- I would also like to remind the committee that there are still questions that have been inadequately answered regarding the stakeholder group set up to decide the future of WILG. It is claimed that the group was united in agreement with the closure of WILG and the transferring of funds to local authorities. This was quite simply not the case. 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 would also like to draw attention to the minutes of a Health and Social Care Committee from January 2014. Stephen Gulliford, the Charging Policy Manager at the Welsh Government. He was talking about the Four Options that emerged from the Stakeholder group and said:

I don't know if I'm allowed to say this, but opinions were stressed that they didn't really trust that the local authorities, if they were given the responsibility, would continue to have the same level of support they receive under ILF currently, although some service users did go for option 4, where a specific grant would be purely for ILF to carry on in the current form, at least with the same level of payment.

Gulliford continues:

Options 3 and 4 obviously found more support through local authorities and local authority organisations,

This supports the theory that I have always had – that the Welsh Government were put under pressure from Local Authorities and merely crumbled because they believed they could save a bit of money and a lot of hassle.

- **#SaveWILG** campaigners have also undertaken extensive **Freedom of Information research involving all Local Authorities**. The emerging picture gives us extreme cause for concern, particularly around inconsistency of approaches and the lack of clear details so that a postcode lottery could be a

serious issue. Subsequently we make the following 11 observations from our findings:

1. **Lack of Awareness:** We sense a lack of awareness or perception about what exactly the local authorities have taken on hence the diversity of responses we are receiving. What preparation or briefing and training has been given to each Local Authority about this transfer of WILG responsibility?
2. **Lack of Statistical data:** Some councils have a lack of even the most basic statistical data. This leads to at least 2 concerns: (a) Are they or will they keep any stats in the longer term? (b) Without stats how will they assess actual progress and achievements, or even refute claims that they are providing a poor service? Of course, it could be that the councils have simply failed to provide a decent quality response to our FOI; but it doesn't inspire confidence.
3. **Failure to analyse or interpret:** Some councils do have the stats but when questioned further they couldn't interpret some basic data in a more definite way. Cardiff state they have assessed 97 % of WILG recipients but they cannot say whether the outcomes in each case will be for more hours of care, or less hours of care, or the same hours as before. This is crucial for a real understanding of what is actually happening on the ground and we expect such data at a minimum. It is not too much to ask. Failure to respond naturally raises more concerns, until we can be presented with the fuller picture.
4. **Care Packages with Reduced Hours:** We are concerned, to note even at the point of transfer and transition that a significant number of individuals are receiving fewer hours of care under their new re-assessed weekly care package. We wonder if costs or expenditure are being trimmed for the most vulnerable in our society who are not best placed to represent and advocate for themselves. We cite Denbighshire, Wrexham, Monmouthshire and Conwy as councils raising concern. What are the reasons for reduced care packages?
5. **Clear Disputes Process:** We have real concerns about any defined disputes process. Clearly not everyone will agree with their new proposed care package, so the route to dispute resolution should be very clear and signposted. Again, the lack of response and the diversity give cause for concern and a feeling of postcode lottery; not the way the service should be operating on the ground. Cardiff Council said they were setting up a new review procedure and Ceredigion refer to a complaints procedure; but are these in line with the Social Services and Wellbeing (Wales) Act 2014? Worse,

at least 2 councils in response to this question simply state with smug satisfaction everyone is happy with the new arrangement (Anglesey and Caerphilly councils).

6. We note the developments at **Powys Council with mixture of hope and concern**. They confirm 59 recipients are to receive a care package with more hours and just 3 to receive fewer hours. This is in line with what we'd expect on the basis that WILG recipients as they get older are likely to need either the same or more care, but very rarely less care, which would suggest they were improving. WILG recipients with a progressive disability will unfortunately deteriorate over the years rather than improve. Furthermore, Powys Council refer to an overspend to deliver the appropriate service. How will this be funded long term? What reassurances can the minister give to these WILG recipients?
7. **Transitional Funding**: In terms of funding we are concerned to note that some councils do anticipate the need for additional funding from the WAG such as Gwynedd Council who put the figure required at £100,000.
8. **Ring Fencing & Long-Term Provision**: We naturally asked about the security of the WILG transitional funding and if it would be ring fenced and also protected against future cuts. Some councils gave no response (Anglesey), most made clear that there was ring fencing of funding up to 31/3/2019, but thereafter three explained that the funding via the RSG (Revenue Support Grant) would be subsumed within the adult social services budget (Ceredigion and Torfaen) or the Community Care budget (Conwy). Again, and of concern was the split between those saying there were no guarantees re the budget (Torfaen, Merthyr Tydfil, Cardiff, Port Talbot), and others who recognised that the local authority had a duty under the Social Services and Wellbeing (Wales) Act 2014 to provide care, which wasn't budgetary (Ceredigion, Rhondda, Caerphilly, Carmarthen and Conwy).
9. **Social Services and Wellbeing (Wales) Act 2014**: Point 8 is crucial if the legislation is to mean anything. Looking ahead local authorities cannot simply reduce the hours of care packages for recipients when times are tight (austerity). Surely these are minimum legal obligations which must be preserved or maintained, as appropriate. Do the social services staff in each local authority understand this fact? Should the minister impress this concern upon the 22 local authorities as a matter of urgency?

10. Ministerial Oversight and responsibility: Having decided to transfer the WILG to the 22 local authorities the Minister nevertheless still has a role of oversight, responsibility and regulation for the conduct of the WILG transition. To what extent is the Minister for Children, Older People and Social Care undertaking that role at this stage? Surely the divergence of approaches and shortcomings we have outlined would give rise to ministerial concern and intervention to get the transition process back on track? Further, if it is the case that the Minister is aware and he accepts responsibility has he in fact intervened in any way? If he has not intervened because he is satisfied with transition progress, on what information does he base that decision? If he has a solid base of transition information from the 22 local authorities, why did you feel the need to ask for the information contained within our FOI's, which is minimal?

11. Finally, to re-enforce the national legislation we refer to the UN Convention on the Rights of Persons with Disabilities guideline (specifically article 19):

Article 19 – Living independently and being included in the community

States Parties to the present 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.

- The short-sightedness of the Welsh Government is also highlighted by developments in Scotland and Northern Ireland where they have recently decided to use the ILF model to support all community living for disabled people. This can be achieved in these neighbouring countries, so why not Wales?
- We have always accepted that WILG has limitations and have always made it clear that once we save the tripartite principle of WILG, our next objective will be to improve on WILG.
- I would like to draw your attention to the situation in England following the closure of the Independent Living Fund 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.

- The publication of [UK Independent mechanism update report to the UN Committee on the Rights of Persons with Disabilities](#) is also of crucial importance. I have provided a link to this report below.

This is a very illuminating document that shows just how far behind the United Kingdom is slipping in terms of Disability Rights. The sections about Independent Living is of particular interest to me and my comrades as it is critical of the current arrangements that we are having to put up with. It provides yet more evidence of the need to save WILG as well as some worrying news that the Welsh Government are rushing through a new framework on Independent Living for disabled people that is bound to be a huge disappointment to those with high care and support needs. Welsh Labour have proved time and again that they do not want to listen to party members, unions, Labour MP's, supporters from across the political spectrum or some of their own politicians and are determined to stop WILG.

I am doing everything I can but I am not being listened to at all. I have been robbed of three years of my life and the effect of this campaign has taken a huge toll on my health.

I will carry on the fight until the bitter end because I believe in what I am fighting for and have no confidence in the Welsh Government – as it stands – to produce a suitable alternative.

The section on Wales, reads as follows:

- **The EHRC is concerned that disabled people's right to independent living may be harmed by the Welsh Government's decision to potentially merge the Supporting People programme with other budget lines from 2020. Concerns have been raised that disabled people's rights have been negatively affected when equivalent funding programmes elsewhere in the UK have been lost.**
- I could go on and on 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.

I wish I could write more but time is at a premium. The #SaveWILG campaign has won so much popular support from across the political spectrum, but the future is still clouded in deep uncertainty. Despite pages of evidence to support our claims, despite Scotland and Northern Ireland retaining their equivalent of WILG, despite the evidence already there to see from England and Scotland, despite the UN report on this, despite Disability Labour passing a motion to save WILG, despite political backing from Unite the Union and others, the membership, Jeremy Corbyn, John McDonnell, Ken Loach, Welsh MPs, Wrexham AFC, the vast majority of Assembly Members, we are still in a state of uncertainty about the future of the Welsh Independent Living Grant. 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/>

UK Independent mechanism update report to the UN Committee on the Rights of Persons with Disabilities.

http://www.nihrc.org/uploads/publications/Progress_on_disability_rights_in_the_UK_CRPD_-_Shadow_Report_2018.pdf

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-ill-plans/>

<http://www.bbc.co.uk/news/uk-wales-politics-38385381?SThisFB>

<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/>

<https://nathanleedavies.wordpress.com/2018/10/09/progress-on-disability-rights-in-the-united-kingdom-savewilg/>