P-05-771 Reconsider the closure for the Welsh Independent Living Grant and support disabled people to live independently - Correspondence from petitioner to Chair, 05.04.18

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Chair
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National Assembly for Wales

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Dear Mr Rowlands,

Thank you for giving me the opportunity to respond to the letter you received from Huw Irancca- Davies AM regarding the planned closure of the Welsh Independent Living Grant (WILG).

I feel like a broken record having to repeat myself time and again. Whatever evidence I provide regarding the disastrous effects of transferring Independent Living funds to local authorities in England, the Minister for Children and Social Care seems to be burying his head in the sand. At the bottom of this letter, I have included links to DWP and Inclusion London studies on the impact of the closure of the Independent Living Fund (ILF). These need to be read and digested to fully appreciate why we should not follow the irresponsible and dangerous path taken by the UK Government.

Please excuse me for having to repeat myself, but I made several key points and raised important questions in my last letter which were totally ignored. Subsequently, I find myself having to raise these questions and observations once again.

Please find attached my previous letter to Huw Irranca-Davies that has not been addressed. With this in mind, I am going to try and make things as clear as possible, in order to emphasise just how serious and important this is:

- 1. With respect to Mr. Irranca-Davies when he says he "appreciates my apprehension", he **cannot** possibly do so. Unless you have to go through this yourself, you cannot even begin to comprehend the difficulties and shear frustration of having to expend all your energy, campaigning for what is right while being ignored by those in power.
- 2. WHY are Welsh Labour making this dangerous change to start with? DEMONSTRABLY this change is not, will not and cannot be an improvement for existing WILG recipients.
- 3. As things stand, even under WILG, I, and every other recipient I know, already believe we have too much responsibility and too much to worry about before we even have to deal with our health conditions on top. The new proposal will mean this level of responsibility will significantly increase. Not only this, but HID seems to not recognise at all that most recipients of WILG will not be in a position to take on these extra responsibilities, worries, admin etc. This seems to have been completely ignored.
- 4. Why not wait until any independent investigation has come to it's conclusions BEFORE subjecting vulnerable people to even more confusing, and unnecessary, change?
- 5. Mr. Irranca–Davies seems very confident, no matter how it is worded or defended, that losing the 'third arm' of the support triangle (the other two being local authorities and the contribution of the recipient themselves) is nothing to worry about. Recipients should not be made to have to battle with hostile local authorities who are only concerned with their budgets. Disabled people deserve independent representation so that they can move forward with their lives with confidence instead of trepidation. Demonstrably, local authorities are wildly inconsistent, and therefore, the consequences of these changes will be highly erratic and terrifying without the support of a third party.

- 6. If HID and his team are working with Social Care Wales, as a WILG recipient, I'd expect consultation for our input and consideration. Disabled people should not be treated as mere objects that need dealing with, but should be involved in matters that will impact on their lives.
- 7. I would like to ask Mr. Irranca-Davies why it is that as a passionate Welsh Labour party member and campaigner, he thinks I should have to suffer like this? Why is it that our own MPs, AMs and EVERY SINGLE PARTY MEMBER CONSULTED, TO A PERSON, is vehemently against the scrapping of WILG? These people are willing to support me consistently, in order to reverse a decision that should NEVER have been made.
- 8. HID admits that he expects these new changes to take time to bed-in. Well, I am afraid time is a luxury I, and many WILG recipients, do not have. As you are aware, I live with Friedreich's Ataxia. The average life expectancy for someone with my condition is 35 years of age. I am 41. I am having to spend what ever time I have left fighting against my own party, against a decision no one outside of the authorities agrees with. That is not fair. Yet, I HAVE to do this as my principles will not allow me to simply sit back and watch, while Welsh Labour ignore all the evidence in front of them and make a grave mistake that will severely damage the disability rights movement in Wales.

This is unbelievably difficult to write. I genuinely hope it is hard to read, too. This is because I am afraid that the people who desperately need to understand, simply do not get it. I think another meeting with Mr. Irranca-Davies is urgently needed. I cannot, and will not, give up the fight.

I look forward to Huw Irranca-Davies' response. Thank you very much indeed for facilitating things Mr.Rowlands, I am grateful to you for doing this.

Yours in hope,

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-livingfund-post-closure-review

https://www.inclusionlondon.org.uk/campaigns-and-policy/factsand-information/independent-living-social-care-and-health/ilf-oneyear-on/

https://www.disabilitynewsservice.com/independent-living-fundshocking-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-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/