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, 29.01.18

Eich cyf/Your ref Petition P-05-771

David J Rowlands AM
Chair
Petitions Committee
National Assembly for Wales

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29th January 2018

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 received a copy of the summary response to the WILG consultation, but in my original response to the Minister involved – Rebecca Evans AM – I challenged her to release the data collected in the consultation **rather than an edited summary**. I feel that the actual responses would provide a clearer picture and avoid any suspicion of doctoring the results to fit the Government's aims.

As time ticks on this situation is getting more and more <u>frightening</u>. I believe a disaster is about to unfold and the Welsh Government does not have the humanity or humility to listen to the fears of disabled people and act accordingly when the **overwhelming evidence** indicates a step backwards for the right to Independent Living.

In 2015, in the report on the consultation responses, we were given the impression that a "successor body" **would** be put in place in the long term:

## "The Minister will reconsider the steps needed to develop a Welsh successor body to the current ILF as a longer term solution."

One of the things that was made crystal clear throughout the consultation and all of the discussions, before and after, is that it is the experience of disabled people and unpaid Carers that some local authorities simply <u>cannot</u> be trusted to translate the 2014 Social Services and Well-being Act into genuine independent living for those who require high levels of support.

The Equality Impact Assessment on the decision to end WILG and hand responsibility to local authorities to assess and fund support for these disabled people asserted that: "Recipients in future will be supported by their local authority based on the well-being outcomes they are seeking to achieve. These will directly support their independent living. As such the rights of recipients to live as they wish will be upheld." and promised that: "Over the period of the two-year transition period the Welsh Government will monitor how each local authority is progressing with its reviews of recipients and the outcomes that result from these. This will be to ensure that recipients have reviews to time, that their future well-being outcomes are being identified with them and that the support they require is being provided rather than separate payments from social care provision."

Unfortunately, some local authorities have been seen to reject the core elements of the 2014 Act and assert that disabled people "must accept whatever local authorities decide for them" and that "disabled people cannot be allowed to tell paid carers how to support them because that would be illegal under health and safety law." Some people who had been granted overnight cover were unable to employ staff because they only had a £30 per night budget – even after the authority had been shown case law on at least minimum wage payment for night working.

We live in an atmosphere of distrust of disabled people due to many years of right wing media representation of disabled people as liars and scroungers and this atmosphere and the attitudes it engenders pervades public life however much that is denied by authorities. Some people in receipt of WILG funding have been told explicitly that once they have been reassessed by the local authority their level of support will be reduced.

Welsh Government's assertion that **everyone's** wellbeing will be protected because of the 2014 Act is naive at best and dishonest at worst. It is no

secret that a Medical Model attitude towards disabled people remains endemic and institutionalised across the public sector and it is clear from the regional needs assessments and particularly Social Care Wales' summary report, that there is no understanding of the distinction between 'being independent' [meaning managing without support] and 'Independent Living' that Welsh Government have formally accepted as meaning disabled people living the lives they choose, in the way they choose and supported how, when, where and by whom they choose. I would like to explain just how worrying the current situation is; with the new proposal not ring–fencing the money, and the removal of the Welsh Government's <u>direct</u> responsibility, the new outcome will almost certainly mean less money/carer hours for me, at a time when I am going to potentially require 24 hour, <u>NON–RESIDENTIAL</u>, care.

If recipients of WILG could see the "transformational change" across social services promised by successive Minsters and nominally guaranteed by the 2014 SSWb Act then I believe fears of unfair and inhuman treatment would to an extent be allayed. Unfortunately, what is experienced is that local authorities vary enormously as to whether their attitudes towards disabled people and genuine Independent Living reflect the 2014 Act or, in some cases, 1980s attitudes and policies that would sentence disabled people to isolation in their own homes or imprisonment in 'care' institutions. People who require support to use the toilet during the night are being instructed to use incontinence materials. People who have no independent mobility are being left in their homes without support for several hours at a time – in fear for their lives should any accident happen and intensely frustrated that they cannot function in any capacity until the next staff come on shift.

However, the other element of the Independent Living Fund was that independent Social Workers carried out the assessments and reviews so that disabled people felt protected by the independent oversight of a qualified and experienced social worker who could not be intimidated by the local authority.

What is needed urgently is a hold on transferring funding into full local authority control; we think although WILG is a much better option than the current proposal, it is something in itself that could be improved. We also note that current proposals do not take into account the capacity of the recipient to take on the delegated responsibilities. This seems to us to be a double-whammy against recipients.

I would like to place on record my thanks to Huw Irranca-Davies for taking the time to come and see me in my home. Can you please also make him aware of this. However, in retrospect, the one thing he did say that has kept me awake at night since, was "I am not here to change policy". I, along with 1,500-odd other recipients, cannot contemplate this remaining as his 'mantra' going forward. This goes right to the heart of the issue-the Welsh Government must realise why this change is not necessary, absolutely not wanted, and not an option. Sorry to be blunt, but we are talking about massive, negatively life-changing consequences. It really is that serious.

Should you need any further information please do not hesitate to get in touch using my contact details above. <u>I would be very grateful if you could ensure Huw Irranca-Davies personally receives a copy of this letter.</u>

## THANK YOU VERY MUCH, I/WE TRULY APPRECIATE ALL SUPPORT & CONSIDERATION

Yours sincerely

Nathan Lee Davies

I have provided some links below to show how we are busy campaigning in the media and the community to Save WILG, despite my own personal high care and support needs:

https://nathanleedavies.wordpress.com/2018/01/26/windfall-for-councils-savewilg/

https://nathanleedavies.wordpress.com/2018/01/24/links-and-updates/

I also include below minutes of a meeting that I had with Huw Irancca-Davies concerning WILG. This meeting did little to address my fears for the future and no one seems to be listening to the voices of disabled people:

https://nathanleedavies.wordpress.com/2018/01/20/minutes-of-meeting-with-hue-irranca-davies-savewilg/