

P-06-1404 Increase clarity and rights for people on direct payments or WILG to live independently - Correspondence from the Petitioner to the Committee, 05 September 2024.

Update to the Senedd Petitions Committee: 16-9-2024

1. The fundamentals of my Petition and campaign remain true, but still to be fully addressed.
2. Dealing with the Social Care Minister's letter to the Chair of this Petitions Committee, I respond seriatim:
3. Her second paragraph is over confident that the current legislation is being applied appropriately on the ground. As a Direct Payments (DP) recipient I can say that the local authority always seems to apply the guidance in their favour, not in support of the needs and welfare of the DP recipient. Local authorities are focussed upon saving money, hence the repeated funding "clawbacks" in my case.
4. The Minister's third paragraph focuses upon the anticipated "future solution". This is good but fails to address problems arising here and now. Bear in mind; "The past is history, the future is a mystery, but the present is a gift." I live in the present.
5. **Independent Intermediaries or Advocacy:** Responding from personal experience, I can say that the offer of an intermediary is neither independent nor strong enough to meet the need of DP recipients. Hence my request for some form of a "trade union" for disabled people. It doesn't have to be a trade union, but we need something.
6. Indeed, lessons were not learnt from the closure of the UK wide Independent Living Fund, when the truly independent advocate existed under a genuine "tripartite" system.
7. **Application of the 2014 SSWBA:** The Minister seems very confident that past legislation will resolve a future problem. She overlooks the existing issue that the legislation, excellent in theory falls short in practice on the ground. The battle between an individual DP recipient and a local council is uneven, where the former invariably must take what they are given, because to fight or challenge is such an uphill task...! I am a fighter; I am supported by my informal care co-operative and still this isn't enough. I have been forced in my desperation to contact Mark Isherwood, MS the Chair of the Cross Party Group on Disability. But not every recipient is either as determined as myself, nor as resolute and resourceful.
8. **The "...best tried and tested forms of local support":** The Minister has misplaced optimism about local authorities always seeking to provide the best support for their local DP recipients. We urge her to engage and learn the lessons now, to come up with the best solutions for the future.
9. In respect of talks with stakeholders about a continuing role for the IPA (?) in CHC DP's, I would like to understand more clearly what is being proposed?
10. **Draft Report: "My Voice, My Rights, My Life":** This has been drafted by the Local Authorities themselves, so that they are effectively "marking their own homework". I have direct experience of the reality on the ground and there has been no

collaboration or consultation with myself or others, who I suspect who would present a different reality.

11. **The Disability Rights Taskforce Independent Living Social Care Working Group:**
The recommendation for a National Centre for Independent Living is very interesting. I would welcome the opportunity to contribute to the subgroup mentioned by the Minister in this penultimate paragraph. I could bring my on the ground, lived experience to this group.
12. I am pleased that the Health and Social Care Committee is progressing with the Health and Social Care Bill. This may provide me with a solution to my current problems in the future, namely by early 2026. However, it doesn't address my issues here and now. More needs to be done.
13. I want to avoid getting drawn into further discussions about a potential future solution for myself and other DP recipients; our issues are occurring now and the Minister, Dawn Bowden is clearly focussed upon the future.
14. There is a juxtaposition of the Minister's future solution and my Petition with current problems which do not neatly overlap. But my issues and those of DP recipients need to be understood and addressed, if we are to avoid repeating the same mistakes in future legislation.
15. I wish to emphasise that the Social Services and Well-Being (Wales) Act 2014 (SSWBA 14) is excellent in theory, but not being faithfully applied on the ground. This must be addressed. The anticipated "future solution" really doesn't deal with the current problems being faced now. And the differences between theory and practice need to be looked at as a matter of urgency, if we are to reach the right solution.
16. The objective of this petition is to resolve current DP issues, thereby resulting in better solutions being created for the future.
17. As of today, the current amount of my latest "clawback" by the council is £3,277.70.
18. I suffer with Friedreich's Ataxia so that I must live in the present not hope for a better tomorrow. I want solutions now; sorry for being persistent or a nuisance. To emphasise; "The past is history, the future is a mystery, but the present is a gift."
19. I wonder if the Petitions Committee or indeed the Minister has considered creating a Commissioner for Disabled People? If this is thought to be both appropriate and necessary for the Armed Forces (announced in the King's speech), why not for disabled people?
20. Paralympians show what disabled people can do when given the opportunity. I am looking for a similar opportunity as I believe I have lots to contribute to our society. The same applies to all disabled people, but we are square pegs trying to fit into round holes at the convenience of other people.
21. The recent experience of Baroness Tanni Grey-Thompson "crawling" of a train at Kings Cross station, epitomises the problems facing all disabled people in 2024; despite all the existing equality legislation, we don't have equality. We need solutions NOW.