

P-06-1404 Increase clarity and rights for people on direct payments or WILG to live independently - Correspondence from the Petitioner to the Committee, 11.03.24

Update for Senedd Petition Committee

I am only able to speak about my own experiences with Wrexham CBC. This is a notoriously difficult Local Authority (LA) to work with, but my fear is that if Wrexham Council can treat a well known disabled activist, like myself, like this then I dread to think what difficulties other disabled people are suffering at the hands of other LA's across Wales. Action is required to shift the balance in favour of disabled people who are often powerless in the face of LA's

1. **#SaveWILG (Welsh Independent Living Grant) campaign:** When I was fighting the #SaveWILG campaign in 2016-19 I feared the transfer of rights, power and resources to LA's, who seem to be unaccountable for what they do and how they treat disabled people. My worst fears have come true.
2. **Need for an Advocate for Disabled People:** Please recognise it is crucial that disabled people need someone to speak/advocate for or on their behalf against difficult LA Social Services Departments. This was always the case with the Independent Living Fund that worked well until it was closed by the UK Government.
3. **Juxtaposition:** The LA is very quick to chase me by email for funds & details of my finances, but they are very slow and poor when it comes to engaging with me about my Care and Support Plan.
4. **Failure to "Co-produce":** Co-production is a one of 5 key principles of the Social Services and Well-being (Wales) Act 2014 (SSWBA 14). There is a fundamental failure by the LA Social Services Dept to "co-produce" the Care and Support Plan with Nathan.
5. **Failure to encourage Voice and control:** This is a fundamental principle of the SSWBA 14, but the LA seeks to minimise it in respect of Nathan. This is an essential building block of the SSWBA 14. For example, Nathan has no control over the way his Care and Support Plan is drafted.
6. **Lack of Support for Nathan's Well-being:** This is the third key principle of SSWBA 14 which again Wrexham LA are failing to prioritise in respect of Nathan. Yet Nathan has just 3 well-being outcomes in the Care and Support Plan drafted by the LA social worker, whereas Nathan's Plan has 14 outcomes planned for the year 2023-24.

7. **Local Authority Failure to Comply with their Own Paperwork:** The LA failed to apply their own guidance in the use and drafting of Nathan's Care and Support Plan. For example, the "Baseline self-assessment measure and the failure to draft any aspect of the Plan in Nathan's own words. Finally, there is no record of Nathan's disagreement with the Care and Support Plan as drafted by the LA social worker.
8. **Failure to Engage and Apply SSWBA 14:** It is Nathan's perception that many LA's are not properly engaging with both the SSWBA 14 specifically and disabled people generally. Through this petition we are seeking to spotlight shortcomings or deficiencies in this process, which currently disadvantage disabled people especially if they are isolated. Nathan wants to put that right and feels that greater training is needed for Social Care staff working for LA's.
9. **Final Evaluation Report of the SSWBA 14:** The Final Evaluation Report of the SSWBA 14 published in 2023 reinforces what we know, understand and suspect. It isn't just Nathan facing these difficulties but a lot of disabled people in various LA's. Nathan feels that he is speaking up for many disabled people.
10. **Independent Assessors from Outside Wales:** Nathan's Complaint submitted in October 2023 was passed by the LA to an "independent" assessor who lived and worked outside of Wales. We suspect that he did not appreciate and understand the different Welsh legislation namely SSWBA 14. This legislation promotes co-production, voice and control and well-being. This is fundamentally different from the English legislation.
11. **Need for a Bespoke Welsh Complaints Process:** We need a bespoke complaints process which would be fair to all disabled people across Wales and which would give them hope when dealing with robust LA's and they find the cards are stacked against them.
12. **Veto:** The LA seems to have a veto over Nathan's Direct Payments, which largely undermines the basic principle of independent living. Further the LA don't seek to facilitate Nathan's wishes, they seek to undermine and frustrate every independent action he takes.

13. **Clawback:** Nathan's virtue of saving money has turned into a vice, as the LA have "clawed back" £33,000 of Direct Payment funds between October-December 2023.
14. **No Pension:** Bear in mind Nathan doesn't have a pension. He survives on a combination of benefits and Direct Payments – which includes legacy WILG money.
15. **Removal of "safety net":** The Local Authority has taken Nathan's accumulated "safety net" of funds which enabled him to employ a team of Personal Assistants (x 9). The uncertainty has made it difficult for Nathan to deal with staff pay, pensions and employer insurance issues.
16. **Query:** Can you accumulate Direct Payments for something you want/need? (Big ticket items such as bike exercise equipment). The guidance suggests you can, otherwise the implication is that a DP recipient must always exist on the breadline. But what if the LA disagrees?
17. **GoFundMe:** Nathan was forced to fund a "short break" with a charity crowdfunder request to the public during this cost of living crisis. Is this how disabled people should be treated in the 21st century?
18. **Unique Circumstances:** Nathan's situation and circumstances are unique; the label "disabled" doesn't make Nathan the same as every other disabled person. Nathan emphasises that all disabled people are different, not the same and so deserve bespoke and personalised care and support.
19. **Nathan's Appeal Ignored:** The LA have appeared to completely ignore Nathan's appeal against the "clawback" of £33,000 of his Direct Payments money. The appeal was submitted in September 2023. The LA did not respond in detail even if they disagreed with Nathan, failing to give full reasons for why they were going to "clawback" £33,000 of his Direct Payment money.
20. **Subject Access Request (SAR):** Nathan submitted a SAR in October 2023 to the Wrexham Social Services Dept to see what information was being held about him. This revealed a few points of frustration, as follows:
21. **Subject Access Request (SAR):** The spelling of Friedreich's Ataxia in the SAR's is incorrect on numerous occasions, not just a typo. The Social worker / staff show either lack of knowledge or respect.

22. **Subject Access Request (SAR):** There is confusion revealed by SAR paperwork over what DP's can be spent upon. See Bundle 9 Page 17 Note 21 of SAR paperwork – reference to a “T bar” to aid Nathan’s sleeping being an anomaly as to who should pay for it; either health department or social services department?).
23. **Subject Access Request (SAR):** The Social workers have just cut and pasted (or auto populated) from old Care and Support Plans without thinking about the evolving needs Nathan has now/today?
24. **Increased cost of the “Short Break” Due to Council Opposition:** If Nathan had been allowed to pay for the “short break” in July 2023 it would have cost £3000. However due to LA opposition; when Nathan finally booked it in October 2023 the price had increased by over £2000. Nathan also lost an original deposit for the trip of £600.
25. **Clarification required in Respect of the status of WILG?** There needs to be clarification in respect of the “legacy” WILG money, the way it may be spent and the entitlement of LA’s to clawback such funds. Question: How much of the £27 million WILG money is left? Is it an annual figure or a declining lump sum?
26. **Fighting for Nathan’s Human Rights:** Given Nathan’s likely shorter lifespan, it is extremely distressing that he is engaged in a constant fight with the LA to assert his human rights. It seems like Nathan must fight the LA for even the most menial or derisory items to make his life and that of his PA’s more manageable and comfortable as they work for Nathan. Nathan has to fight to live on a level playing field to exist on the same terms as the rest of society. Nathan has had to be prescribed beta blockers by his GP to help deal with the stress.
27. **Disabled People are an Easy Target:** It is our perception that Nathan and many other disabled people across Wales are perceived by LA’s as an easy target, who will not be able to fight back and defend themselves. As a result, they suffer a lack of social care, a lack of provision, and a lack of resources, or a cynical “clawback” as in Nathan’s case. Would society allow any other segment of the population to be treated or abused in such a way?

28. **Social Care Ombudsman:** Nathan is minded to present a complaint about his treatment to the Social Care Ombudsman in due course. This is a never-ending process of struggle, which threatens to overwhelm Nathan and his voluntary, informal care co-operative team.

Nathan Lee Davies

11-3-24