
Senedd Cymru | Welsh Parliament

Y Pwyllgor Iechyd a Gofal Cymdeithasol | Health and Social Care Committee Bil

Iechyd a Gofal Cymdeithasol (Cymru) | Health and Social Care (Wales) Bill

Ymateb gan Nathan Lee Davies | Evidence from Nathan Lee Davies

Response to Senedd consultation on Direct Payments & Social Care

1. **3.45** – I’m not convinced Direct Payments (DP’s) do always allow voice & control; it’s not guaranteed. I have found that my Care and Support Plan isn’t being written to meet my “assessed eligible needs” and thus I cannot spend my Direct Payments on things (outcomes) I want & need. I’ve been beset with clashes with the local council Direct Payments dept over what I’ve been spending my DP’s upon. I cannot get my voice & control heard & acted upon. There has been no “co-production” over the writing of my Care and Support Plan.
2. **3.47** – DP’s for Continuing Health Care (CHC) would be fully funded by the NHS under CHC. Forgive my cynicism, born of experience, but even if free at the outset, what is to prevent the introduction of a small charge within 5 years? Could this be the thin end of a wedge? My contribution to my DP’s is under constant pressure from the local council to be increased, almost annually. I have resisted, but it’s a constant battle.
3. **3.48** – This is a cause of concern and caution. If I was to be assessed eligible for CHC, then I couldn’t necessarily go back to receiving DP’s from my local authority; so I risk losing the status quo if I agree to an assessment for CHC, but then decided I didn’t want to go down that route. I really do feel my voice and control is again under threat. What confidence can I have that there will be “co-production” under CHC to consider and address my health and well-being needs and living outcomes?
4. **3.52** - Adding DP’s for persons with CHC needs so as to give them recipient voice and control isn’t inevitable. The more people that are involved the more confusing things can get. Re the care and treatment for my foot I receive advice from 3 directions; a plastic surgeon, a podiatrist and a district nurse. They have given me conflicting advice about care and treatment and my foot has got worse. My DP’s haven’t given me voice and control. I don’t seek flexibility; I want certainty. Control of the money via DP’s doesn’t inevitably give a recipient voice and control or ensure “co-production”. My focus has been upon trying to get some control over my Care and Support Plan.
5. **3.54** – I am dubious over this claim that the introduction of DP’s for those in receipt of CHC would inevitably give them voice and control, or real “co-production”. It isn’t inevitable and it’s not logical that this predicted outcome would be the result! It could simply be the case that voice and control is largely handed over to the NHS or domiciliary care agencies. As everything is driven by money, so the party that can deliver a service cheaper, thereby saving money and making profit or reducing costs all too often will become the driver of the type of service

provided. The recipient of the DP's is merely a pawn in a process of monetary transaction buying from what is available; eg competition or the lack thereof...The price goes up or the service comes down.

6. **3.55** – Fairness, equality, voice & control. These are good policy principles but not inevitably good in practice. All too often the opposite is the case.
7. **3.56** – Voice and control and person centred care. These are good principles but not inevitably good in practice. The recipient can be controlled, steered and out maneuvered.
8. **3.57** – Co-production. These are good principles but not inevitably good in practice. We still have individual (disabled) recipients taking on larger bodies and organisations so there is not equality of arms.
9. **3.58** – Intended Effect – Laudable principles and objectives, but not inevitable. This is a repetition of the SSWBA 2014 with almost identical principles and objectives, but the theory isn't uniformly happening in reality on the ground. Hence the need for new legislation; as nothing is inevitable. We are at risk of passing voice and control to the NHS or other care provider. The staff need training for this “brave new world” under this Bill so as to avoid the mistakes and difficulties occurring under the current legislation. Hence the need to tighten the implementation of the SSWBA 2014.
10. **3.59** – These outcomes are not inevitable or guaranteed. You are creating a market where the “buyer” has the money, but still doesn't have the control.
11. **3.93** – Amendments to the SSWBA 2014 – These amendments do not deliver the principles of the 2014 legislation such as voice and control, well-being or “co-production”. This is what needs to be addressed. Social services departments are simply not delivering on the ground.
12. **3.104** – The Part 4 Code of Practice of the SSWBA 2014 isn't working. I struggle to secure voice and control, co-production and my well-being needs being addressed. The Final Evaluation Report on the SSWBA 2014 stated at para 6.60: “For the majority of service user and carer respondents interviewed for this evaluation, their experience was one of frustration. Against the hope offered by the Act, they perceived a series of barriers. These included a relatively ‘tokenistic’ approach to listening, power imbalances between themselves and professionals, the need to constantly chase professionals for support, and a lack of recognition of their rights especially around issues of cultural sensitivity among others. These barriers served to work against the experience ‘offered’ and ‘promised’ by the Act’s underlying principles.”
13. **3.106** – DP's to a “nominated person” – I have concerns about this. If this was akin to a “power of Attorney” for people who were not of sound mind, this might make sense. In my case I am of sound mind and run a small business employing 10 Personal Assistants (PA's) and I have no wish to pass that responsibility to a nominated person.
14. **3.111** – This paragraph sets out a laudable objective, but this isn't the inevitable outcome. The need is less for a representative for the DP recipient, but more for a union or powerful advocate that is equipped to fight the corner of the DP recipient, who is all too often alone and isolated and frankly outnumbered by the institution they are up against. See example at 15 below.
15. **EXAMPLE:** The Wrexham Direct Payments Dept had contacted me about visiting me to discuss some of my DP's. They hadn't gone into any detail about the purpose of the meeting, so I wasn't sure what this was all about. 2 staff turned up – “good cop, bad cop” and they proceeded to give me a letter, which they expected me to read and digest immediately. I was shocked and taken aback, as were my PA and support (care co-op), such that I had to take a beta-blocker to stave off a panic attack. Their intent was to “claw-back” £1,314.01 of my DP's. This was outrageous behaviour akin to sending round the bailiffs to take goods from my house without proper warning. I am still dealing with the consequences of matter to the present day.

16. **Care Inspectorate Wales (CIW)** – I am not sure what the exact role of the CIW is, but they have not offered me any help, nor been of any use to me in my adversities of the last 6 years. Perhaps they should have a more pro-active, defined role in regulating the work of the local authorities and promoting the voice of individuals having difficulties with local authorities over DP's and social care? Something more akin to a trade union role.
17. The CIW undertook an inspection of Wrexham social services (24-10-23 to 2-11-23) and the council declared they had a high rating. I would directly challenge that rating by the CIW, but I was unaware of the inspection taking place. I presume most other disabled people were also unaware, so that we couldn't provide a more full and fair picture of the social services provided by Wrexham local authority. We are voiceless and therefore unable to let the CIW know about our "lived experiences" under local authority social care, which remains problematic.
18. I'm concerned that a lot of this legislation is about saving money, but far less about making the original legislation SSWBA 2014 work in the ways it was intended.
19. **CAUTION:** Service providers are in this business for the money (profit) and rather less so for the needs of recipients of DP's.
20. I've had bad DP's as I try to live the life I want to lead. I understand CHC is about nursing. However DP's should amount to more than that. I seek to live my life via DP's in my home in the way I want to. That's not happening as I struggle with resistance from the council. I wonder how LHB's would support me as I spend my DP's in the ways I wish to.
21. **7.148** – Option 1 (loss of DP's, if you are assessed as eligible for CHC with the NHS) This is my concern. Hence if I had a poker hand I would not twist, but I'd have to "stick".
22. **7.155 – 7.165** – All about costs, savings and estimates - I'm not fully convinced by the figures about cost savings based upon estimates. But also concerned that this places the focus in the wrong place. It's not all about costs, profits & savings but actually needs to be about voice and control, health and well-being and co-production, the original principles of the SSWBA 2014, which are failing to be carried out on the ground. See the 2023 review of the SSWBA 2014 legislation which recognised the difference between theory and practice.
23. There is a real risk of allowing a continuation & even an extension or exacerbation of the current problems so that the failings of DP's are merely extended into the CHC sector. It is like a "monetization" or "marketization" of the DP care recipients, who become part of a transaction which remains beyond their control. These are individual disabled people coming up against local authorities, or with option 2 CHC via the NHS and both have different goals and objectives. The former want decent care and support but the latter ultimately want to save money or to make a profit. This is against a backdrop of the legislation SSWBA 2014 which isn't being fully understood or carried out in practice in terms of the original 5 principles (voice and control, well-being, co-production in particular).
24. This Bill aims to take the profit motive out of children's social services, but it isn't being taken out of adult social services. I'm not actually arguing that profit should be taken out of adult social services, but we need to understand where the motivation lies within these "transactions" and thus who really has the power.
25. **If you give people a budget (DP)** - that doesn't make them an expert in social care or CHC and they are still at the mercy of or will be buffeted by the realities of the service providers which may be good or bad or few and far between. Just consider any service providers in our current lives: dentistry, estate agents, GP practices, banks, energy providers, schools and so many other service providers. To what extent do we "shop around" and indeed to what extent is it practical to "shop around"? In many cases it's too late to shop around after a bad experience, or simply inertia / better the devil you know simply keeps you taking the service from the current provider. And remember that the recipients in every case under consideration are suffering

under a disability which puts them at a greater disadvantage to the average member of the public seeking a service.

26. **Back to my lived experience:** My issue about DP's is with the local authority about the way my DP's can be spent, or indeed saved to spend on a "rainy" day. I cannot change my local council for another local council. The amount of money remains the same. But the local council has seen ways in which they can save money or reduce expenses by "claw-backs" of my DP's. They are driven by an incentive to save money.
27. **What I need is support, back up or a "trade union" for disabled people** who will fight my corner and defend our rights or entitlements. The uneven struggle is the disabled person versus the local council or under CHC the NHS. The organisation has all the power and the resources to throw at the situation, so that the individual almost certainly cannot win. Examples of this fight: sub-post masters V the Post Office in the horizon scandal, the UHB (University Hospitals Birmingham) NHS Trust scandal, University Hospitals Sussex Foundation Trust police enquiry, Grenfell Tower scandal, Hillsborough scandal & the NHS contaminated blood products scandal. In all of these cases individuals have been beaten down, outnumbered and out resourced by a large organisation which has protected itself. Fairness, justice and solutions or resolution have only come with: (a) publicity (b) realisation that there are often lots of other victims (c) whistleblowers (d) and even then add a decade of campaigning!
28. Where are the regulators to investigate and to call rogue parties/organisations into line? Who is standing up for David against Goliath? Where is the CIW when you need it?
29. **Current petition to the Senedd Petitions Committee on this subject:** It is titled: Increase clarity & rights for people on Direct Payments or WILG to live independently. My Petition calls for fairness and:
 - Better advocacy support & a national organisation to represent the voice of Direct Payment users
 - Dispute resolution process
 - Better communication channels
 - LA Complaints panels to have knowledge of Welsh law & policy
 - Re-training LA staff in the spirit and intent of the SSWBA 2014 Act
30. My Petition is next under consideration by the Senedd Petitions Committee on 24-6-24. And hence why I wanted to be a part of this consultation process to share my lived experience.
31. Money alone doesn't really empower people, especially the disabled to ensure they have rights and entitlements such as voice and control, well-being and "co-production" as envisaged by the SSWBA 2014 and that's what needs to be addressed. These are basic human rights which disabled people are entitled to.
32. My care is good because I use part of my DP's to employ good carers. But everything else around my DP's has gone disastrously wrong. I cannot choose to have a "short break" in Florida, so I had to "crowd fund" that recent trip. There is a breakdown or disfunction between the receipt of my DP's, what I am allowed to spend this money upon, and my Care and Support plan which fails to address my health and well-being outcomes, because I still lack voice and control and there is no co-production"; the SSWBA 2014 doesn't work for me on the ground.
33. **EXAMPLE:** I do not have a pension, but with DP's the local council apply a crude "Goldilocks" principle: I shouldn't have too little money; but I mustn't have too much money; I am only allowed to have just the right amount of money. That's living on a tightrope, which is a very uncomfortable place to be. It seems, according to the council, but not as a matter of law, that I am not allowed to save/accumulate DP's for a rainy day. But a rainy day for a disabled person is both likely to happen and also much more difficult to cope with than for a person without any disability.

34. So much has gone wrong with the passing of the ILF (Independent Living Fund) and the WILG (Welsh Independent living Grant).
35. **Scottish Independent Living Fund (Scottish ILF)** – Contrast the situation elsewhere in the UK. Recognising they had issues to be resolved with the power imbalances and the administration issues etc, Scotland chose to relaunch and indeed widen their ILF to new recipients. This took place 3 months ago.
36. It is also very instructive as to what the Scottish ILF is allowed to be spent upon; buying and securing a much wider variety of services, skills, teaching and opportunities designed to truly empower the disabled recipient and also giving them real voice and control, benefiting their well-being and clearly “co-production” is at the heart of this process.
37. **7.179** - I agree we need more support for DP recipients. But that will have to go beyond changes intended in this legislation. Disabled people are all too often kept in the dark.
38. **7.186** – It’s interesting that CHC recipients appear to be motivated to get better value with their DP payments. I have managed my DP’s responsibly, however as I save and accumulate money the local council have been remorseless in trying to “claw back” any funds not being spent. In other words my responsible and cautious spending of my Direct Payments has been punished; can this outcome be avoided under CHC with DP’s via LHB’s?
39. **7.190-7.191 and 7.195** – It seems to be a presumption that introducing DP’s for CHC via LHB’s leads inevitably to improved fairness, independence, voice and control, care-related quality of life and psychological well-being. But my lived experience with DP’s via the local authority suggest that this is not inevitable. There is a missing element of training and shared understanding about the rights of a disabled person to live an independent life and to have “co-production”, voice and control viz-a-viz the LHB providing CHC.
40. Currently I have DP’s but I do not have voice and control, nor “co-production”.
41. **9.22** – There isn’t a link or guarantee that DP’s **will** deliver voice and control. That is based upon a false assumption that voice and control, wellbeing and “co-production” follow the money, which we know is not the case. We know that the SSWBA 2014 with great principles isn’t always being applied in practice on the ground. The government, through this Bill must fill that gap with training, information and more support for disabled people. Perhaps that support should include a Disability Support Unit designed to help people navigate their way around the law, rules and guidance about this and other Acts so that they can understand the options and make informed choices.
42. **Summary** –
- This legislation looks like a move in the right direction, towards the NHS and LHB’s whilst making DP’s available for CHC. But I don’t believe this Bill addresses the entire problem, namely the failure to apply the 5 principles of the SSWBA 2014 on the ground.
 - I have been in two minds about my options when this Bill becomes law...?
 - But in the absence of sufficient certainty and fullest information it’s a case of “better the devil you know”; albeit that I perceive my local council social services department extremely negatively.
 - So please plug the information gap for myself and other disabled people so that we are recognised as informed decision makers and not flapping in the dark.
 - Ultimately disabled DP recipients are at a massive disadvantage against big local councils or local Health Boards and we need someone to be there to speak up for and defend us, similar to a trade union. Otherwise we will always be at a disadvantage regardless of money.