

**P-05-1106 Introduce Personal Health Budgets and Personalised Care in Wales,  
Correspondence – Petitioner to Committee, 06.03.21**

Dear committee,

I have included a short video of my news interview. also i have included a copy of my response in word document format for ease of use. see appendix for testimony's.

<https://www.youtube.com/watch?v=s12H34rB8VQ>

thanks

Mr Rhys Bowler

Thank you for your letter responding to the petition regarding the introduction of Personal Health Budgets and Personalised Care in Wales. It is refreshing to know that the Welsh government has acknowledged our struggles as people will advance care needs. And how hard we have fought for 24 hour care within our own control not governed by anyone only our want to control our destiny the way we want it! Using my own personal experiences as an example of the damage that not having 24-hour care does, I hope I will demonstrate to you how this legislation must change and change quickly.

- This decision must be made with the utmost haste as many of us with advanced care needs, and life limiting conditions, have short lives, and our conditions are often incurable and progressive. The clock is ticking for us, far quicker than the rest of society.

***“My life is limited, and I wish to live it, not spend my time fighting the welsh government for a right which I believe, should have naturally been bestowed to me. In 2017, I watched my poor brother die of this awful condition. He was 27, we hardly left the house because of how little care hours we had! We merely sat in his bedroom, and pondered the life we could have had, if we didn’t have Duchenne Muscular Dystrophy, and what we wished we could accomplish, if we had the right care! That was no life for my brother, his potential was trapped and wasted. I want to live before it’s too late for me also, and fulfill my vast potential.”***

***“My complex care needs clearly mean I require 24/7 care, from at least my local authority, and my health needs undoubtedly make me eligible for CHC. I am dependent on a ventilator; without it I would die! However, I have my reasons for staying away from the CHC assessment! I have been repeatedly warned what would happen if I underwent the assessment and went to CHC. Ministers, it should never be a threat that if my health deteriorates, I will lose control and autonomy over my life! I would be forced to have a care agency who are not commissioned by myself, I could not decide who provides my care, whether I choose to employ my***

***own personal assistants (as I have successfully done all my adult life), or commission an agency. To my mind this is completely unacceptable”.***

**Reference Rhys Bowler letter to Julie Morgan shadow health minister.**

This Current pandemic shows the fragility of human life and indeed how short truly it is! It has offered the non-disabled populace a new perspective on what it means to be imprisoned within their own homes. My greatest fear which has me utterly terrifying is that the world will be coming out of lockdown and I will be still Here stuck as a prisoner remaining in my isolation, without the care I need to get out of my home and live. It really makes me feel disheartened, and hopeless.

### **Key points**

***“The clear, unambiguous expectation in Wales is for personalised, seamless integrated health and social care that enables individuals to maintain voice and control where they wish to.”***

- This currently falls short when it comes to individuals with complex care needs, who require CHC funding, and those who have joint funding, (additional NHS funding alongside local authority funding.
- We have no voice or control over our care, when we are not able to receive direct payments under NHS Continuing Healthcare (CHC) and do not have the ability to choose who cares for us.
  
- Although we are proud welsh citizens who because of devolution have to be seen as individualised, but we must have parity with England and Scotland in terms of care. And Have the same opportunities as they do we are after all a united kingdom.
- Bringing a welsh PHB into reality, and facilitating a direct payment format of care funding, would see the severely disabled people of Wales given the same rights and freedoms, that exist in the rest of the UK.
- However, by not having the PHB here in wales, the welsh government are disabling us further! It goes completely against the social model of disability, which has been written and was addressed in a speech by the shadow minister, Jane Hutt, on international disability day.

***“We understand the importance of continuity of care for these individuals, especially those who are most vulnerable, have complex health and social care needs and those that require intimate care. The prospect of losing their team of personal assistants, who may have been providing care to them for a number of years, is understandably very distressing to them”.***

## **When I go to continuing healthcare! The NHS preferred care method would be an agency!**

I can tell you from my point of view, and the people I represent, we absolutely do not want agency care, to be forced upon us!

- Agencies often struggle to provide, the individualized support, many like myself require.
- They dehumanise, the individual that should be at the heart of it.
- They do not have our best interests at heart!
- And there are many more issues, which I could talk about for hours, but at the heart of nearly all the problems is money and control.

***“The fact of the matter is, not having the ability to choose who provides our care, is very distressing, for countless reasons”.***

### ***Reference Rhys bowler speech to Jane Hutt***

- My needs are complex, but I do not require medically trained staff. I have a team of skilled personal assistants, who I employ myself. I have been doing this for 15 years, and I do not want to lose them, or the self-worth I get being an employer, and managing my own care. I merely need the additional joint funding via direct payments, to enable me to cover 24/7 care, rather than my current 108 hours.
- In my fight for my own care and others, I have received legal advice, and been told I should not be made fearful that my future is in the hands of the local authorities and the local health board officers, who erroneously believe that Direct Payments cannot be facilitated.
- Julie Morgan wrote in a statement to all, that there should be an unambiguous statement from Welsh Government, to health boards and local authorities, stating they must work together to meet people’s needs in a person-centred way. Continuing NHS Healthcare: The National Framework for implementation in Wales. Enabling individuals with care needs that require CHC funding to be able to maintain their independence, and facilitate them to keep their personal assistants, if that is their choice.

Some Welsh health boards have agreed, in principle, to look at adapting how it can provide joint CHC funding, in the event that individuals are assessed as eligible for CHC funding. Alternatively, if individuals are not fully funded by CHC, and their care and support continue to be provided in a joint package of care, health boards have agreed to work with local Councils to ensure the continuation of existing care packages, through direct payments.

In relation to Direct Payments, the Welsh Government’s 2014 Framework guidance advises (paras 4.46 – 4.50):

- ... If an individual has existing DP arrangements, these should continue wherever and for as long as possible within a tailored joint package of care.

I believe this clause needs strengthening in the interim, to allow Direct Payments to be made more easily attainable, and available to those with joint packages of care. After the pandemic, these individuals should not fear that this will be taken away. I urge you to implement this immediately.

### **Our thoughts on the proposal by the Welsh government, to implement an independent user trust.**

- An IUT is described as similar to a PHB! It isn't.
- IUT's are in fact one of the methods, that an individual can use to manage a PHB, when a direct payment is not possible.
- So not a PHB, and not direct payments provided by the NHS.
- IUT's are not equal to PHB's as they don't provide us with a direct payment, giving us the choice of managing and purchasing our care directly. Putting us in control
- IUTs, totally obscure the idea of independence.
- IUTs fail to put individuals, at the heart of the decision-making process, instead taking away our choice and control over our care, which surely, we deserve.

**“We are committed to looking at different options around the interface between CHC and direct payments, including how direct payments may be used for CHC recipients, which would be equivalent to personal health budgets”.**

### **We are strongly believe that direct payments supplied by the NHS the way forward for Wales as;**

1. It is a format that 100s of disabled individuals and their families are comfortable and familiar in using.
2. It provides a clear, unambiguous expectation that Wales wishes for a personalised, seamless integrated of health and social care, that enables individuals to maintain voice and control where they wish to.
3. If it is Wales intention is to pursue joint care packages, between local authorities and the NHS. Then it ensures consistency and a seamless merger of the two establishments in a familiar already proven and effective format.
4. If the reasoning for not implementing PHBs or an equivalent to allow the NHS to supply direct payments, is the possible misuse of NHS finances, then you merely have look at the individuals like myself, who will receive them, and thus achieve autonomy.
5. We are accountable adults, who have self-control over our lives, and finances, so why suggest, we are now incapable of taking care of our care finances ourselves. We have been providing tax returns, and documentation of how we utilise our funding, since we first received direct payments from our local authorities. The only thing that

makes us different from everyone else, is a physical disability, you should empower us, not discriminate.

6. A person who appreciates the funding as much as we would, would not abuse the system!
7. Independence to me and others with complex care needs, is as valuable as the very air we breathe, a direct payment provided by NHS to us, would be more precious than gold! We could live without the fear of inadequate care, from profit seeking care agencies, and thrive by giving us the choice of managing, and purchasing our care directly, through the channels that we choose. Putting us in control.

**“We will look at long term legislative options as well as considering any interim arrangements that could improve voice and control for CHC recipients in the short term”.**

*“There are exceptions to the rule where direct payments have been granted for CHC and joint package recipients. I have seen it! I have witnessed it! I know it can happen! Cwm Taff health board have repeatedly said that it can’t happen, I know that this is untruthful! This maybe the hundredth time I am stating this! Why can I not be granted an exception? Whether if maybe Covid 19 that is allowing these direct payments or otherwise! Why can I not be granted an exception? I am deteriorating now! I have been deteriorating for the past 10 years! Yet I cannot get an increase from my local authority and I cannot get direct payments for the NHS! Minister how long must I wait!”*

*Reference Rhys Bowler letter to Julie Morgan shadow health minister*

- During the pandemic some recipients of CHC and joint packages were granted special exceptions whereby the NHS supplied direct payments.
- These people are now used to having their care under their control and have discovered a more efficient way of having the care provided.
- Those recipients now need reassurance that their direct payments won’t be taken away from them when pandemic is over.

### **My Personal Ordeal!**

*“I’ll tell you one scenario, which I’m not just talking about if my ventilator cuts out unexpectedly, which would quickly lead to my demise, but a day that started off ordinary. My carer had just left after a quick call to feed and toileting me.*

*I was very tired, and cold, as is often the case after physically exerting myself: being moved about and repositioned during toileting is tiring, and my muscles don’t retain heat very well. I needed to regain heat again quickly, or I’m not able to drive my chair. My usual solution to this problem, is my trusty hairdryer, which I keep on a table near my workspace: it’s positioned at the appropriate height to warm my hand up, controlled by a switch linked to my environmental controls, which I drive over to switch it on!*

*Switching it on was successful as normal, “why wouldn’t it be, I do this all the time?” I warmed my hands and after a few minutes, they were more than comfortably warm, and I went to switch the hairdryer off.*

***The unthinkable happens! The power on my chair had cut out on me! I was going nowhere! Stuck 3 inches away from the searing heat of the hairdryer! My own personal hell began, it felt like an eternity!***

***I could smell my skin was slowly cooking, my sentimental silver bracelet which I have always worn with pride, became an instrument of torture! It bore deeper into my blistering, slowly roasting flesh. The heat now so intense that it dried my tears, as they fell. My screams of agony muffled by the drone of the dryer. It is a hopeless feeling, when you know no help is coming for 5 hours I prayed, and I pleaded for an end to my agonizing ordeal. Eventually my prayers were answered, as my electric ran out, cutting my tormentors power supply! Leaving me in sweet blissful silence, and cold darkness. My ordeal was finally ended, with a carer arriving and calling an ambulance.***

***I still get nightmares to this day, it scared me physically and mentally, and almost succeeded in slaying my independence as it temporarily turned me back into a child, who needed his mother! But me being the man I am, I quickly regained my hunger for independence.***

***I told you this story, not for sympathy but so you can understand me more and see the lengths I am willing to endure to keep my independence!"***

**Reference Rhys Bowler presentation to cross-party disability group.**

## **Conclusion**

Please help us to change the system for the good of those who wish to keep their independence, a God given human right which the government should be more than happy to bestow to us! We should not have to fight for this! I believe with your support to push for the implementation of PHBs, we can work towards an NHS Wales we can all be proud of and not just because of the bravery they've shown during the pandemic. Whose policies are more inclusive, more robust, and fit for the future? Let's make Eniran Bevan a proud welsh man's dream a true symbol of freedom just as our country has done for century's!

Appendix.

## **Testimonies**

***"I have a progressive muscle wasting disease, and have 24/7 care. Three years ago my life was torn from under me, as I began using NHS funding, and was told wrongly, that I must have an agency, and my direct payments stopped. Three agencies failed, and my independence was destroyed, my family relations were pushed to the limit, and my mental and physical health suffered. I have fought, with legal help, to get direct payments back via my local authority, with joint funding, which I now have. I live in fear that this will be taken away, and when my health needs become greater, I will be refused direct payments again and lose my wonderful and skilled staff. I'm the expert in my care, and agencies have proven not to be able to provide the support I need. A PHB or its equivalent would give me the option of using direct payments even with full CHC, and help me retain my fought for independence, I could continue to choose who cares for me, and thus get the***

*best individualised care for me. I beg you to bring in this legislation, as quickly as possible, and reinforce the current framework to ensure joint packages can be facilitated and continue to be provided through direct payments. I fear for myself and others with complex needs, as we are being stripped of our choice and control over our care, because we live in Wales”.*

Reference [REDACTED], condition Limb girdle muscular dystrophy 2e, Hails from Llandudno Conway.

*“I was fully able bodied before my disability in effect I had my life taken away from me. My condition means that all four of my limbs are affected, and comes with reduced hand function and mobility! I am now reliant on a wheelchair and have to be hoisted by carers. There are lots of manual handling and care support tasks needed in my daily life i.e. drinks, food prep, catheter care, bowels and managing medication! If these routines and maintained rigidly I can get symptoms of autonomic dysreflexia. Which is a very serious condition and is hazardous to my health! If ignored it could lead to a stroke and even death. Stating the obvious I can’t manage this on my own which is why I’m in need of 24 hour care. And liked Rhys bowler I cannot get it! I am not prepared go into environment where I lose all control over my care and independence. Currently I have 53.75 hours from my local authority but I obviously need more.*

*The reasons why the PHB should be brought to Wales in my opinion, is firstly as they’ve stated in the care act to promote independence to have a voice and say/ Choice in who provides my care. To have a better quality of care. To have the care I deserve which I am entitled to! It shouldn’t be a luxury whether or not somebody should have it, and have a life of independence and freedom. I want the same opportunities I had before my disability. I’m still the same person just sitting down now! My injury was traumatic as you can imagine! And enough of a burden. My life shouldn’t be a burden as well. More importantly it will prove that my chair isn’t stopping me from fulfilling my life! To have some normality to achieve the life I had before this injury. Currently I have lack of support to get me where I want to be.*

*My message to Vaughan Gething Mark Drakeford and the Welsh government is, I want to live! I want to be present! I want to be part of a community! I want to work! I want to be happy. I want to be healthy enough, so I can access more physio and become physically and mentally stronger. I want to get off antidepressants medication and mental health services! I want to get out of my bed and not feel so depressed. Please grant us our freedom and allow the NHS to supply direct payments”.*

Reference [REDACTED], Condition Transverse myelitis. Hails from Bridgend

*“Like Rhys I also suffer with Duchenne Muscular Dystrophy. I feel if you introduced a PHB in Wales it would be greatly beneficial to a lot of people as it would enhance care needs and give individuals a lot more choice and control of what best suits their care needs. With a care agency they try to dictate to you what will best suit you’re care needs also they can be unreliable as in can let you down by saying there’s no one to cover shifts etc. you’re not really given a choice of who comes to you. I’ve had my fair share of issues with the*

*care agency I have and also with my health board so I feel as though I'd benefit with a PHB."*

Reference [REDACTED], condition Duchenne Muscular Dystrophy, hails from Pontyclun

### **How it is in England!**

*"I have Duchenne, like Rhys, and I'm at a similar level of progression of the condition. I've had challenges getting funding before, but unlike Rhys I had the option of getting a personal health budget PHB. I had a PHB since 2014 providing me with 24 hour care, but allowing me to have the choice over who cares for me, when they change shifts, and what they are allowed to do. It's not without challenges managing a care team, and you have to do it professionally, but with a good team in place I have independence and freedom to live my life, work and have a real social life with my partner. It's mind-boggling that Wales hasn't introduced PHBs yet - there's so much evidence that they work, and have been implemented really well in certain areas."*

Reference [REDACTED], Condition: Duchenne Muscular Dystrophy, Hails from Redding

*"I have an ultra-rare/unique condition that my consultant calls a 'neuromuscular plus' condition, as it has features of other conditions too. I may never get a diagnosis, but my genome has been sequenced so maybe one day they'll find out what it is. It means I have multiple organ failure, I am dependent on near-constant intravenous drips including TPN (IV nutrition), IV fluids and IV medications, I have a double lumen Hickman line giving access directly into my bloodstream and the tip of this line sits just inside my heart, I have a PEG draining my stomach 24/7, I have an Ileostomy (stoma bag) and a Urostomy (aka an Ileal Conduit, another stoma bag), require daily nebulisers and at times, assisted coughs with an LVR bag, I have buccal and patch medications, I use a powered wheelchair for mobility but need to spend a lot of time in bed. I live a full and active life, I work multiple jobs including working for charities, working as an independent advocate and support broker, project management, research work, consultancy and speaking, and I have my own business.*

*I live at home with my mum Kate and Assistance Dog Molly and I have a Personal Health Budget for 24 hour care.*

*I have:*

*16 hours per day (07.00-23.00) with a Band 5 or Band 6 Registered Nurse who we have trained in all my needs (as TPN and central lines are a specialist skill, not a universal skill, even for nurses)*

*8 hours overnight (23.00-07.00) with a PA*

*6 hours doubled-up with a PA alongside the nurse during the day (variable timings depending on activity/need).*

*The reason I have nurses is because of the my TPN and IVs not being able to be a delegated task - well, in some areas TPN alone can be delegated to PAs but not the mixing and preparation of intravenous medications and administration via a central line, plus also there is a lot of clinical judgement in my care including fluid management and when to give extra IV fluids and how much, whether and when to give IV Paracetamol (there's no set fever level), when to give IV antibiotics and how many doses to give, how to manage pressure care and wounds, etc.*

*However, I have had 2 PHBs in my lifetime. In early 2014 I became one of the first people in Essex to be given a Personal Health Budget, but despite my needs being nursing based, they wouldn't fund nurses and so my mum was told if she wasn't prepared to do all my round the clock IVs and TPN, she could "dump [me] in a home". So I fought for my mum to be paid to do my nursing-based tasks, since they couldn't be managed otherwise and mum couldn't continue working full time and caring full time (she used to have to keep popping home from work to do my IVs), eventually - after a fight they agreed to pay mum 3 hours a day to give 1 infusion (despite doing IVs 24/7) and that was enough for mum to give up work and do most of my care.*

*Sadly, in 2015, my mum was diagnosed with a brain tumour and we had 3 weeks between her diagnosis and her surgery to put in place a 24/7, mostly nursing based care package. The CCG tried every which way to force me into a nursing home, but 6 days before mum's op, they finally relented and gave me a package. I should really have 24 hour nursing (as overnight the PA can do nothing to help if my drips go wrong or I need an extra IV) but 16 hrs nursing and 8 hours overnight care was sufficient to manage my needs for 6 weeks whilst mum had her op and recuperated (yes, my mum was expected to go back to caring 24/7 6 weeks after brain surgery!). Unfortunately, my mum suffered a brain haemorrhage and then a catastrophic stroke after her operation. I had to fight to make my emergency package permanent. I had an agency providing the care (6 days was not long enough to set up a new PHB!) and I hated it, the agency weren't great, I had no control or autonomy, they kept sending unsuitable staff, one nearly making 4 fatal errors had I not stopped her and despite this fact, the agency tried to continue sending her, all but 1 of the 35 odd carers they sent between 2015 and 2018 used to sleep on shift despite being an awake night, leaving me waking up my poorly, recovering mother to wake up the carer to care for me. Nurses weren't much better. After about 3 months from that permanent extension, I said "I want a Personal Health Budget again, when can I go back on a PHB?"*

*Finally in 2018, I moved my care worker support onto a PHB (Phase 1) and employed my own PAs, then this year (during lockdown) Phase 2 of my PHB was signed off and my directly employed nurses started. It's a shame covid happened as otherwise my nurses would be transforming my life and giving me more independence from mum and I'd be able to do so much more now I had my own nurses and no agency, but their support will make an impact once life goes back to some version of normality.*

*PHBs transformed my life. They allow me choice, control, freedom and flexibility to make my care work for me and to have the ability to be flexible in how the support is provided. I am able to choose who looks after me, what they do and how my care is provided. I can live the life I want to lead with my PHB. I even got aromatherapy massage training for my nurses and PAs funded in my new PHB to help with my pain relief. My PHB is saving the CCG (health board in Wales) over £100,000 per year compared with agency care. PHBs allow us to make better use of resources whilst giving me the control and choice I need.*

*I cannot understand why Wales does not have PHBs! There's so much evidence of their positive impact.”*

Reference [REDACTED] Hails from Essex

*“As similarly to Rhys I'm a fellow chap living with Duchenne Muscular Dystrophy and at the age of 36 I'm pushing the boundaries of what was originally expected life expectancy wise. As a resident of England I have access to a personal health budget, which has allowed me since 2013 to use money allocated to me to pay a care company to provide me with a bespoke package of carers/assistants I have chosen myself to do 2 12 hour shifts daily including awake at night. This has allowed me to have a life as independent as possible and enables me to do whatever any able-bodied person would do including living in my own home and trips both domestically and in Europe. I was unaware that our friends in Wales such as Mr Bowler did not have a possibility of such care, I feel that everyone should be able to live life to the full, something that a PHB definitely does. Hopefully we can make enough noise for the Welsh Assembly to take notice and make a change.”*

Reference [REDACTED], Condition: Duchenne Muscular Dystrophy, hails from Cornwall