

Submission to the Petitions Committee

Submission by Ann James and Luke Clements¹ further to the invitation of the Petitions Committee of the Welsh Parliament of the 31 March 2022.

We thank the Petitions Committee for its invitation of the 31 March 2022 to comment on [Petition P-05-1106](#) 'Introduce Personal Health Budgets and Personalised Care in Wales' and the issues it raises.

Background information

Over the course of the last two years, we have provided advice and clarification on the law and statutory guidance to Rhys Bowler and Sam Strickland concerning the above Petition. Both have felt threatened and powerless in the face of local authority and local health board responses to their individual needs. Their primary objective is to maintain their independence and control over their care provision through a Direct Payment either via a jointly funded (local authority / NHS) package of care or as a fully funded NHS Direct Payment when they transition to fully funded Continuing NHS Healthcare (CHC).

Rhys Bowler initiated the petition in August 2020 to 'fight' for Personal Health Budgets (PHBs) in Wales which would offer the same right to maintain choice and control over care provision when in receipt of NHS CHC funding.

In due course the Welsh Government set up a CHC and Direct Payment Working Group. Rhys Bowler and Sam Strickland were, we understand, co-opted onto this Group. In April 2021 they sought our advice in order to enable them to respond to a questionnaire that had been sent to them and a copy of their response is attached.

In the Spring of 2021, a draft revised NHS CHC Framework was published with a consultation period ending 21 August 2021. It was, in our opinion, a deeply disappointing document and we posted on the Rhydian pages a short note making this point. The note can be accessed at <http://www.lukeclements.co.uk/nhs-continuing-health-care-and-direct-payments-in-wales/>.

In August 2021 the Welsh Government published what it intended to be a 'final version' of the NHS CHC Framework, with an implementation date in 2021. This however turned out not to be the final version. In 2022 the Government indicated that minor amendments were required and a final version was then published in March 2022² with an implementation date of April 2022.

Our response to the final version has been posted on the Rhydian pages at <http://www.lukeclements.co.uk/the-end-game-continuing-nhs-healthcare-chc-in-wales/>.

¹ Ann James is a retired social worker who has worked in local government. She spent a significant part of her career as a social work academic at the University of Bangor and Luke Clements is Cerebra Professor of Law and Social Justice at the School of Law, Leeds University. Ann and Luke set up Rhydian: Social Welfare law in Wales in September 2017. Rhydian aims to be a critical commentary concerning social welfare law in Wales. The web pages provide exposition and clarification of the law in Wales <http://www.lukeclements.co.uk/rhydian-social-welfare-law-in-wales/>.

² For reasons we cannot understand, it states that it was 'published' in July 2021.

Analysis

We understand that there are strong arguments in Wales concerning the potential that PHBs may have to undermine certain underpinning principles of the NHS. We also appreciate that there are practical obstacles to introducing PHBs in Wales – as this would almost certainly necessitate new legislation. Inevitably legislative reform of this kind would take time, during which period those who believe that PHB's are vital to enable them to maintain their independence and control, would continue to be without such an arrangement.

While there are undoubtedly considerations that favour the maintenance of a prohibition on NHS Direct Payments in Wales – the current arrangements in Wales have the potential to seriously undermine the human rights of individuals such as Rhys and Sam: the right to respect for their private and family life (Article 8 of the European Convention on Human Rights) and the right to independent living (Article 19 of the UN Convention on the Rights of Persons with Disabilities). Utilitarianist arguments should not trump fundamental human rights and it is incumbent on the Welsh Government to act decisively to avoid such situations.

We believe that the current measures in Wales, for individuals in the situation that Rhys and Sam find themselves, to be wholly inadequate. In practice the working relationships between a number of health and social services bodies concerning NHS CHC funding arrangements are not good and ever greater exhortations by the Welsh Government on this question will not rectify the problem.

It is for this reason that we have argued consistently that the Welsh Government should ensure, not only that its NHS CHC Framework promotes the use of Independent User Trusts (IUTs) – but that its (current) rhetorical references to IUTs be buttressed by detailed practical / workable guidance on the process of setting up and maintaining such Trusts. In our opinion, it is essential that this guidance contains a template example of such a Trust: a template that is as simple as is possible and one that prioritises the maintenance of the individual's independence and control over their care provision and not one that prioritises the administrative convenience and priorities of the NHS body. Ideally the Trustees of the IUT would be appointed by the individual beneficiary or, if this is not practicable in a particular case, a Centre for Independent Living or similar entity would fulfil this role.

For the last five years we have been drawing attention to the potential for IUTs to be a meaningful mechanism for addressing the problems caused to individuals such as Rhys and Sam. During this period the Welsh Government **and** the local health boards have failed, in our opinion, to grasp the nettle and to develop practical / workable guidance of the kind outlined above.

We hope that the Petitions Committee and its individual members can take action to break this impasse.

Ann James

14 April 2022

Luke Clements