

P-05-1106 Introduce Personal Health Budgets and Personalised Care in Wales, Correspondence – Petitioner to Committee, 03.03.22

Thank you for revisiting our petition for a Personal Health Budget in Wales.

After multiple meetings, letters and conversations between the government, Rhys Bowler, myself, and others in the working groups. I feel disheartened and utterly let down by the Welsh government. Speaking as a person with complex care needs, who lives independently in my own home with 24/7 care, this new revised framework does not go far enough. There is a strong emphasis on individuals requiring continuing health care going into care and requiring nursing care. The fact is many people who require funding through a joint package or solely CHC, do not require nurses! Where are the allowances for these people? And surely anyone requiring CHC funding will ALWAYS require social funding too. We have a life, we need to have social care be as important as healthcare, we don't cease to live independently because we require more care.

The framework is essentially no different from previous versions. Joint packages and IUTs are again just given a courtesy paragraph, and the suggested move towards the freedom of a Welsh care funding system, akin to the English PHBs is nowhere.

Yet again we are told we are given voice and it will be person centred, but actually, it reads and will be used, to take away our power, independence and choice.

The authorities and government should be encouraging independent living, not institutions wherever they can.

We are left feeling hopeless for our future, and unheard yet again. Are the government moving at all in the right direction?

We have enclosed articles from Luke Clements and Ann James, who have given us guidance throughout. Hopefully, their superior legal knowledge, and discussions of actions that can be implemented now, can be heard by the government, where our pleas have not.

Regards

Samantha Stickland and Rhys Bowler

Continuing NHS Healthcare and adults Briefing by Luke Clements ~ updated February 2020.

Section 47 of the 2014 Act is concerned with the contested question of 'Continuing NHS Healthcare' – for which Wales has particular problems.[1] In an attempt to address some of these problems, in 2014 revised guidance was issued Continuing NHS Healthcare: The National Framework for Implementation in Wales[2]). At the time of this update (February 2020) the outcome of consultation on updating the Framework was awaited

In relation to this question both the English and Welsh Bills commenced with the same phrasing. However, a number of amendments were made to the English Bill to ensure that the current boundary between local authority responsibilities and the NHS (as defined in the Coughlan Court of Appeal judgment [3]) remained unchanged. Sadly, no such amendments were made in Wales. The

result is a potentially serious problem, since the wording in the Act is materially different to the wording used by the court in Coughlan.

The Coughlan judgment confirmed that local authorities were prohibited from funding nursing care that the NHS was required to provide but that they could fund nursing care if it was (1) merely ancillary or incidental to the provision of social care support and (2) of a 'nature' that one would expect a social services authority to provide. Although section 47 makes it unlawful for local authorities to fund nursing care unless it is 'incidental or ancillary' to social care, it contains no prohibition in relation to the second element – namely as to the 'nature' of the nursing care'.

In the absence of firm action by the Welsh Government, LHBs will inevitably seek to argue that the Act materially undermines the rights of patients to 'Continuing NHS Healthcare' funding. Unless this is the (unstated) intention of the Welsh Government, this failing will need to be addressed directly in the regulations and in the Code. A clear statement would also be welcome – on the lines of the statement made by the English Minister that:[4]

The provisions [in the English Act] are not intended to change the current boundary—let me place that clearly on the record—and we do not believe that they will have that result. The limits on the responsibility by reference, as now, to what should be provided by the NHS remain the same'.

It is however strongly arguable that the silence of the Welsh Government on this question (and the lack of any formal adjustment in the funding allocations for health and social care in Wales) is best interpreted as evidencing an intention that the health / social care boundary remain unchanged by enactment of the 2014 legislation.

NHS and Direct Payments

In *R (Harrison) v Secretary of State for Health and others* (2009),[5] the High Court held (in an English case) that the NHS Act 2006 did not permit direct payments to be made by NHS bodies. Although in England the Act has since been amended to allow direct payments, this is not the case in Wales.

It is arguable that *Harrison* was wrongly decided. An appeal against it was withdrawn when the case became academic due to the implementation of the right to direct payments for NHS patients in England (patients eligible for continuing care funding). The argument that *Harrison* was wrongly decided concerns the fact that the 2006 Act does not expressly prohibit direct payments – the judge simply decided that it should be interpreted as not permitting such payments. If the courts were confronted with a strong human rights case (where for example someone is being threatened with forced institutionalisation) then the Act would have to be interpreted 'so far as is possible' to give a human rights compliant meaning. Such a case would rely on the public law obligation to comply with Article 8 of the European Convention on Human Rights (respect for private and family life) and the commitment of the Welsh Government to adhere by the principles in the UN Convention on the Rights of Persons with Disabilities (and Article 19 in particular).

In *Gunter v SW Staffordshire PCT* (2005) [6] Collins J held that there was nothing in principle in the NHS Acts to preclude a health body making direct payments to an Independent User Trust (IUT) which would then make arrangements for the health care needs of the profoundly disabled 21 year old applicant, stating:

It seems to me that Parliament has deliberately given very wide powers to [health bodies] to enable them to do what in any given circumstances seem to them to achieve the necessary provision of services. I have no doubt that this could involve the use of a voluntary organisation such as an IUT as the supplier. There seems to me to be no difference in principle between an IUT set up specially for a small number of persons or an individual and a nursing or other agency so far as the defendants are concerned. It would obviously be necessary for a member of the defendants to be a trustee so as to ensure that money was properly and prudently spent.

Where a person is jointly funded by a LHB and local authority, then there would appear to be nothing in principle for the local authority not to make the direct payments and in so doing, to use funds transferred to it by the LHB (as its contribution) in pursuance of its powers under NHS (Wales) Act section 194.

Where a LHB is unreasonably refusing to be flexible in relation to such payments (i.e., concerning the use of an Independent User Trust or to use its powers under section 194 of the 2006 Act, it is incumbent on the Welsh Government to intervene to resolve this deadlock. In such a case the Government could – for example – direct a recalcitrant LHB or an NHS Trust by using its powers under sections 12 and 19 of the 2006 Act.

[1] See for example, Wales Audit Office Report Implementation of the National Framework for Continuing NHS Healthcare 13 June 2013.

[2] Welsh Government Continuing NHS Healthcare: The National Framework for Implementation in Wales (2014).

[3] R v. North and East Devon health authority ex p Coughlan [2000] 2 WLR 622: [2000] 3 All ER 850.

[4] Public Act Committee Report 16 January 2014 (page 205/208).

[5] [2009] EWHC 574 (Admin) 23rd March 2009.

[6] [2005] EWHC 1894 (Admin) 26/08/05.

[7] Welsh Government Continuing NHS Healthcare: The National Framework for Implementation in Wales (2014).

NHS Continuing Health Care and Direct Payments in Wales

Disabled People in Wales of all ages who are eligible for NHS Continuing Health Care and who want to remain living in the community – have been left without a legal route to retain control of their care and support through a Direct Payment.

The Welsh Labour Party manifesto (p.18) stated an intention ‘to work with the Disability Equality Forum to improve the interface between Continuing Health Care (CHC) and Direct Payments (DP).

The Government has set up a Working Group to consider this 'interface' and to offer solutions. However, by suggesting that there is a way of 'improving' the interface' is a curious – if not confusing – turn of phrase. It holds out the idea of there being a remedy to this fraught situation – albeit one that the Welsh Government and Local Health Boards (LHBs) have signally failed to propound for over a decade.

The remit of this group is unclear and can only be seen as a gesture to people with complex health needs that the Government is wanting to work with them to achieve a solution.

Surprisingly, the matter of NHS CHC and Direct Payments has not been attended to in the revised 'draft' framework and this is a significant oversight. Welsh Government has been aware of the impact on many disabled people of the legal constraints on providing Direct payment for NHS Continuing Health Care for many years as outlined by the Welsh Government Director of Social Services in his letter of February 2016.[1]

The section in the draft Framework (para 6.52. – 6.55) is wholly inadequate to address the problems experienced by individuals who are eligible for NHS CHC and who wish to retain the benefits of the flexibility, choice and control provided by a direct payment arrangement.

Once an individual is eligible for NHS CHC, the terms of section 47 Social Services and Well-being (Wales) Act 2014 make it unlawful for a local authority to provide support under the 2014 Act and (as the draft Framework states at para 2.10), the LHB becomes responsible for providing a 'full package of health and social care' for that individual. NHS law as it applies in Wales does not permit LHBs to make direct payments equivalent to those made by local authorities under the provisions of sections 50-53 of the 2014 Act. This is a legal 'fact' and referred to as such in the following account.

The new framework should state this explicitly – that under the law as it exists in Wales, that when an individual is assessed as eligible for NHS CHC, it is unlawful for direct payments to be provided to the individual to enable them to purchase the health and social care needs that they have been assessed as requiring.

The framework should not try to disguise this fact by saying "it is not unlawful for local authorities and health boards to work together to provide individuals with voice and control in respect of their health and social care needs. This includes the pooling of budgets and other mechanisms to ensure people experience seamless care."

The above statement creates confusion for recipients and potential recipients of NHS CHC and creates an expectation of LHBs and LAs that they are legally constrained from delivering.

The Framework must provide 'grown up' and explicit advice as to how this problem is to be resolved: legally resolved and resolved to maximise the well-being of individuals. The framework needs therefore to: (1) address the cultural problem within the NHS which obstructs flexibility, choice, and control; and (2) provide practical advice as to what can be done.

The impact of this 'legal fact' and the failure of the Welsh Government and LHBs to take positive remedial action means that many disabled people, their families, and carers experience severe and unnecessary disruption / harm to their fundamental rights: harm measured in terms of loss of employment, education, training, leisure, normal independent living opportunities, distress and anxiety. This impact engages fundamental human rights for example Article 8 of the European

Convention on Human Rights (respect for private and family life) and Article 19 of the UN Convention on the Rights of Persons with Disabilities ('CRPD') – the right to independent living.

These rights require a cultural change in the way NHS commissions support to address the complex community care and support needs of disabled people – since a failure to do this may leave individuals with no realistic option apart from institutionalisation.

Currently disabled people who are assessed as having primary health care needs are being forced to relinquish their hard fought for rights to manage their own care in Wales. For many in Wales who see disabled people in England having the right to continue with managing their care through a Direct Payment this is difficult to understand and accept.

Both LHBs and LAs are adversely impacted by the amount of administrative time taken trying to resolve situations where individuals are refusing to be assessed for NHS CHC – out of fear of the loss of their direct payment and with this the loss of the benefits this arrangement provides for them – notably flexibility, choice, and control over their care arrangements. In many contexts it appears that the current inadequate arrangements mean that LHBs gain financially at the expense of LAs. This is due to the fact that many individuals who are de facto above the legal limits of social care (in terms of s47 of the 2014 Act) remain funded by LAs because they refuse an NHS CHC assessment and LAs feel compelled to continue their funding (albeit illegally) because of the severe impact a funding withdrawal would have on their fundamental human rights.

This may also lead to many needs that have been identified and are eligible for NHS Healthcare are not met because the LA is not able to or prepared to fund these needs. This will consequently leave people with an inadequate response to their assessed and eligible needs for care and support.

The barriers that stand in the way of LHBs providing direct payments to individuals who are eligible for NHS CHC do not derive from the Framework – but from the NHS legislation in Wales and the effect of section 47 Social Services and Well-being (Wales) Act 2014. There are no 'flexibilities' proposed in the Framework for overcoming this problem. All the Framework does is to: (1) state what can be done if a person is not eligible for fully funded CHC (see below); and (2) to use meaningless platitudes to suggest that somehow a 'spirit of co-production' can resolve the legal problem or that somehow the loss of a right to a direct payment can be assuaged by being told that they have not in fact 'lost their voice, choice and control over their daily lives'. This is an utterly unacceptable approach for major guidance when there is a widespread consensus that this is an issue engaging fundamental human rights.

Jointly Funded LHB and LA Packages of Care

It is imperative that NHS CHC is not confused and conflated with a joint package of health and social care provision.

Joint funding arises where a person is not eligible for fully funded NHS CHC but has substantial health care needs. These health care needs are assessed as being beyond the powers of a local authority social services department.

In these circumstances, the revised Framework should set out that a Direct Payment is a choice afforded to all disabled people who are assessed as having both health and social care needs that is funded by both the local authority and local health board – and that the full costs of the community package (including the community ‘nursing’ costs) can be funded by way of a direct payment.

This should be supported by clear and unambiguous guidance to LHBs and LAs about funding of joint package and the mechanism that needs to be established should people wish to continue with a Direct Payment or indeed choose a Direct Payment to organise their care and support.

A Joint Package of LHB and LA care should not become the default in Wales to circumvent the lacuna in Welsh legislation or a resistance to using a legal solution like an Independent User Trust. Nor should it be used to quieten the resistance of disabled people who are at risk of losing their right to manage their care through a Direct Payment because their needs are above the legal limits of social care. This will potentially leave people without their eligible needs being met and having to pay for their social care provision when in fact they are eligible for an NHS Healthcare package which is free at the point of delivery.

Fully Funded NHS CHC packages and Independent User Trusts

The Welsh Government has the option of amending primary legislation to allow for NHS funding to individuals through a direct payment for NHS CHC (i.e. on the same lines as in England). Even if this was a serious consideration it will not be a solution in the short /middle term.

In the current legal situation, it appears that there is only one uncontested way of addressing many of the problems resulting from the absence of a provision in Welsh NHS law providing for the making of direct payments – namely the use of Independent User Trusts (IUTs). IUTs were first developed as a mechanism to overcome the absence of a right to direct payment for social care (i.e. prior to the Community Care (Direct Payments) Act 1996.[2] In *Gunter v SW Staffordshire PCT* [2005] EWHC 1894 (Admin) Collins J held that there was nothing in principle in the NHS Acts to preclude a health body making direct payments to an IUT which would then make arrangements for the necessary support needs of the individual.[3] The trustees in such an arrangement could be a Centre for Independent Living, the disabled person’s family or friends or some other support organisation.

IUTs have been promoted by disabled people’s organisations [4] as a way of addressing the problem of direct payments not being available from the NHS. In England, prior to the national rollout of a right to direct payments for disabled people living in the community who were eligible for NHS CHC funding, the Department of Health issued guidance on the use of IUTs.[5] What is needed is for the Welsh Government to issue similar – but updated – guidance and for this to include a simple template example of an IUT.[6] It is unreasonable (and could lead to significant inequalities) to expect each LHB to develop separate templates (and guidelines for their use) – and also unlikely, since none have (so far as we are aware) notwithstanding this is a long-standing problem.

The delay in providing guidance as to how IUTs can be developed and used by disabled people to enable them to enjoy their independent living entitlements is unconscionable and (given the widespread recognition of the role IUTs can play) and there is no reason why further delay should occur (i.e., delay by suggesting a ‘pilot’ when IUTs are already a legal option).

The draft Framework needs to be revised and guidance provided to LAs and LHBs without further procrastination. The impact on individuals makes it incumbent on Welsh Government to fulfil its manifesto promise.

[1] Welsh Government Director of Social Services and Integration dated 10 February 2016.

[2] See for example L Clements and P Thompson *Community Care and the Law* (Legal Action Group 6th ed 2017) paras 10.104 – 10.109.

[3] See also Rhydian *Social Welfare Law in Wales Direct Payments and NHS Continuing Health Care* .

[4] See for example, A Holman and C Bewley *Trusting Independence: a practical guide to independent living trust* (Values into Action 2001) and J Fitzgerald *Using independent user trusts to manage personal health budgets* (Mitchell James Ltd 2011)

[5] Department of Health *Personal Health Budgets Guide. Options for managing the money* (DoH 2012).

[6] A simple precedent for an IUT was, for example, provided in L Clements *Community Care and the Law* (Legal Action Group 4th ed 2017) at page 888.