

PURPOSE OF THE CHC & DP WORKING GROUP

As we progress this work we will need to consider the following questions.
Can you please provide your response to these questions in bullet form by **12th May 2021**

1. What are the specific issues we need to address?

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 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The section in the draft guidance (para 6.52.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 s47 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.*"

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

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| | <p>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.</p> <p>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 (2) provide practical advice as to what can be done.</p> |
| <p>2. What are the impacts of these issues on individuals, their families and carers?</p> | <p>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.</p> <p>These rights enshrined in Art.8 of the HRA and the in Art 19 of the UN Convention on the Rights of Person with Disabilities require a cultural change in the NHS that can support the complex community care and support needs of disabled people as the real consequence that this failure may be that an individual is faced with no realistic option apart from institutionalisation.</p> <p>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.</p> <p>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.</p> |
| <p>3. How do these issues impact LHBs and LAs?</p> | <p>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 <i>de facto</i> above the legal limits of social care (in terms of s47 of the 2014 Act) remain funded by LAs because they refuse</p> |

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| | <p>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.</p> <p>This may also lead to many needs that have been identified and are eligible are not met because the LA is not able to or prepared to fund these needs and an inadequate response to assessed and eligible needs for care and support.</p> |
| 4. What are LHBs and LAs currently doing to provide solutions to these issues? | <p>At present it appears that LHBs and LAs currently doing very little to provide practical solutions to this problem – but are in fact wasting a great deal of administrative time trying in some situations to resolve the individual’s concerns and to reach an inter-agency arrangement to address these problems. In other situations, the absence of a legal solution means that disabled people are left feeling anxious, threatened and accepting inappropriate care provision.</p> |
| 5. What does the revised Framework say about the delivery of person centered CHC and the interface between CHC and DPs? | <p>The sections in the revised Framework concerning this problem are wholly inadequate – as noted above under section 1.</p> |
| 6. What are the barriers that stand in the way of LHBs using the current flexibilities within the Framework to provide the outcomes individuals want? | <p>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 Social Services and Well-being (Wales) Act 2014 s47. 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 on utterly unacceptable approach for major guidance when there is a widespread consensus that this is an issue engaging fundamental human rights.</p> |

Jointly Funded LHB and LA Packages of Care

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.

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.

7. Solutions that can be included in the Framework at this time

Welsh Government has the option of amending primary legislation to allow for NHS funding to individuals through a direct payment for NHS CHC.

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 (ie 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

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](#) .

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| | <p>organisation. IUTs have been promoted by disabled people’s organisations⁴ 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 to expect each LHB to develop separate templates – and also unlikely, since none have (so far as we are aware) notwithstanding this is a long-standing problem.</p> |
| 8. Whether any proposals included in the Framework should first be trialled with a specific pilot cohort. | <p>The delay in providing guidance as to how IUTs can be developed and used by disabled people to enable them to enjoy their independently living entitlements (rights enshrined in Article 19 CRPD) is unconscionable and (given the widespread recognition of the role IUTs can play) there is no reason why further delay should occur through the trialling of this (already legal) option</p> |
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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.