

Law Centre (NI) Response to the All-Party Parliamentary Group for Terminal Illness' Inquiry into the Legal Definition of Terminal Illness



May 2019

1 Introduction

- 1.1 Law Centre (NI) welcomes this opportunity to respond to the All-Party Parliamentary Group for Terminal Illness Inquiry into the legal definition of terminal illness. This issue was highlighted to us by a leading cancer charity in Northern Ireland who contacted the Law Centre (NI) through our social security advice line.
- 1.2 Law Centre (NI) promotes social justice and provides specialist legal services to advice organisations and disadvantaged individuals in social security, community care, immigration and employment law. Law Centre (NI) convenes regular Adviser Network Meetings across NI for welfare rights advisers and convenes the Welfare Reform Group, which is an umbrella grouping of organisations that campaign for positive changes to policy, service provision and legislation for persons in receipt of social security. As co-convenors of the *Cliff Edge NI Coalition*, we are working in partnership with over 65 organisations concerned about the cessation of the current welfare reform mitigations in Northern Ireland.
- 1.3 Law Centre (NI) has addressed the issue of the application of the current criterion through its advice line. The current definition of terminal illness ('the 6 month criterion') raises the following issues:
 - the potentially detrimental impact on the mental health of terminally ill claimants.
 - that the effect of the six month criterion is that benefits are refused to individuals with a terminal illness who cannot establish this criterion with reasonable certainty as a result of the unpredictable trajectory of their condition, albeit that death may occur within 6 months.

2 Consideration of the Six Month Criterion in NI

- 2.1 The Independent Review of PIP, carried out by Walter Rader on behalf of the Department for Communities ('DfC') concluded that the six month criterion was unfit for purpose. In June 2018, the Review noted:

That the clinical judgment of a medical practitioner, indicating that the claimant has a terminal illness, should be sufficient to allow special rules to apply. The 6 months life expectancy criterion should be removed.¹

- 2.2 Also in June 2018, representatives from six political parties in NI (SDLP, DUP, SF, UUP, Alliance and Green Party) wrote a joint letter to the Permanent Secretary of the Department asking that a working group be established with the DfC to begin the preparatory work

¹ Walter Rader, 'Personal Independence Payment: An Independent Review of the Assessment Process' (June 2018) <https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-pip-assessment-process-june-2018.pdf>

required, including an analysis of the implications, of the introduction of a definition of terminal illness based on clinical need, rather than any time-restricted understanding of life expectancy.

2.3 In November 2018, DfC provided an interim response to the Rader Review, indicating that:

Under the statutory framework provided for in the Northern Ireland Act 1998 social security law in Northern Ireland is maintained in parity with provision brought forward by DWP in Great Britain, unless the Executive and Assembly determine otherwise. While the Department acknowledge the opinion of the reviewer, it will be of incoming Ministers to determine if they wish to initiate any review of current arrangements²

2.4 According to DfC policy, if someone is awarded PIP as a result of terminal illness there is no review of the award within 3 years.³ There is a clear conflict present in this process in that someone cannot qualify unless death is expected within 6 months but there is an acknowledgment that survival may exceed 6 months and therefore no review should be carried out within 3 years.

2.5 In Scotland consideration of this issue resulted in the removal of the 6 month requirement from the definition of terminal illness. Pursuant to its devolved powers, the Scottish Parliament recently passed the Social Security (Scotland) Act 2018. Schedule 5 paragraph 1 requires that regulations on eligibility for disability assistance adopt a definition of 'terminal illness' which is based on the judgment of a registered medical practitioner. This provision appears to be in line with the recommendation made by the Rader Review.

3 The Impact of the Six Month Criterion on Terminally Ill Claimants

3.1 The six month criterion hinders the ability of people affected by terminal illness to receive the support that they need.

3.2 Some claimants have expressed concern that by making an application and relying on a DS1500 in order to receive the enhanced rate of PIP will indicate that they have psychologically "given up". The following case study, featured on BBC NI in autumn 2018, underscores concerns of the potentially negative impact on claimants.

A claimant in NI was diagnosed with cancer and, after receiving the Disability Living Allowance (DLA) for a period, she was notified that she would have to be reassessed for PIP. She refused to get the DS1500 signed, saying that complying with this "degrading" requirement would be like "signing her death warrant".⁴

3.3 The effect of the six month criterion is that benefits are payable to individuals with a terminal illness who can establish with reasonable certainty that death can be expected within 6

² Department for Communities, 'Review of the Personal Independence Payment Assessment Process: Department for Communities' Interim Response' (November 2018) p14 <https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-interim-response-to-pip-independent-review.pdf>

³ Department for Communities, 'Review of the Personal Independence Payment Assessment Process: Department for Communities' Interim Response' (November 2018) p14 <https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-interim-response-to-pip-independent-review.pdf>

⁴ BBC News, 'Lynette Mchendry 'asked to sign cancer death warrant' (11 November 2018) <https://www.bbc.co.uk/news/uk-northern-ireland-46050474>

months; but benefit is refused to individuals with a terminal illness who cannot establish this criterion with reasonable certainty as a result of the unpredictable trajectory of their condition, albeit that death may occur within 6 months.

- 3.4 The system favours claimants with a predictable disease trajectory, such as some types of cancer. Cancer accounted for less than a third of deaths in Northern Ireland in 2016,⁵ but it represents over 90% of local PIP claims awarded under Special Rules for Terminal Illness. This suggests that a large number of people with other terminal illnesses are not accessing PIP under the Special Rules.⁶

A claimant in NI who was diagnosed with motor neurone disease was unable to apply for PIP under the fast-track Special Rules for Terminal Illness because she doesn't have a medical prognosis of six months or less to live. This claimant expressed her sadness that, because of the six month criterion, people with terminal illnesses are forced to spend their time fighting against an unfair system rather than being able to spend time with the people they love the most.⁷

- 3.5 Marie Curie in its evidence before the Rader Review identified this particular difficulty:

For many terminal illnesses, particularly non-cancer conditions like motor neurone disease (MND), chronic heart failure, chronic obstructive pulmonary disease and dementia, accurate prognosis can be difficult because of the unpredictable trajectories of these conditions. The rate of progression can vary, and patients may be expected to live for a longer period but die within six months due to a sudden decline in their condition.

4 Potential challenges to the Six Month Criterion

- 4.1 The six month criterion in Northern Ireland is contained in primary legislation (Article 87(4) of the Welfare Reform (NI) Order 2015). Therefore, further amending legislation would be required to remove the 6 month criterion. Law Centre NI is of the opinion that in the absence of amending legislation passed by a functioning Assembly, the legislation is still potentially open to challenge, either as a breach of the European Convention on Human Rights ('ECHR') or, alternatively, by virtue of the principles of Administrative Law:

- 4.2 In summary, there may be merit in the arguments that the imposition of the 6 month criterion and the manner in which this impacts on particular claimants, and/or those potentially eligible for the benefit, breaches Article 1 Protocol 1 and/or Article 8, ECHR, read in conjunction with Article 14, Article 1 Protocol 1 ECHR on a freestanding basis, as well as common law principles of Administrative Law.

⁵ Northern Ireland Statistics and Research Agency (2017). Registrar General Northern Ireland Annual Report 2016. Available at: <https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/RG2016.pdf>

⁶ Marie Curie, 'Marie Curie briefing: Personal Independence Payment and terminal illness' <https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/northern-ireland/pip-special-rules-for-terminal-illness.pdf>

⁷ Marie Curie, "I shouldn't have to spend my time fighting for support" (January 2019) <https://www.mariecurie.org.uk/blog/the-struggle-to-get-benefits/221392>

4.3 Subject to any legal challenge to the application of the current test, Law Centre makes the following proposals for next steps in NI and urges the All Party-Parliamentary Group ('APG') to adopt the following recommendations.

5 Recommendations

- Law Centre (N) recommends that the APG supports the introduction of a definition of terminal illness based on clinical need, rather than any time-restricted understanding of life expectancy and urges Westminster to review the position.
- Law Centre (NI) recommends that the APG, whilst recognising the devolution arrangements, urges the DfC to progress the review by the Department of the 6 month criterion and its impact on terminally ill claimants.
- Similarly, Law Centre (NI) recommends that the APG supports the call for a working group to be convened composed of the main political parties, relevant civil society organisations and the DfC to initially scope what preparatory work may be required, pending a ministerial direction to proceed. This would facilitate a timely response should ministerial direction be secured and would include preliminary analysis of implications of the introduction of a definition of terminal illness based on clinical need.

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