

SOCIAL SECURITY (TERMINAL ILLNESS) BILL

EXPLANATORY AND FINANCIAL MEMORANDUM

INTRODUCTION

1. This Explanatory and Financial memorandum has been prepared by the Department for Communities (“the Department”) in order to assist the reader of the Bill and to help inform debate on it. It does not form part of the Bill and has not been endorsed by the Assembly.
2. The Memorandum needs to be read in conjunction with the Bill. It does not, and is not meant to be, a comprehensive description of the Bill. So where a clause or part of a clause does not seem to require an explanation or comment, none is given.

BACKGROUND AND POLICY OBJECTIVES

3. Currently fast track access is provided to five different social security benefits (Attendance Allowance (AA), Disability Living Allowance (DLA), Personal Independence Payment (PIP), Employment and Support Allowance (ESA) and Universal Credit (UC)) where a person is “terminally ill” within the definition set out in legislation governing these benefits: a person is “terminally ill” at any time if at that time the person suffers from a progressive disease and the person's death in consequence of that disease can reasonably be expected within 6 months.
4. In these circumstances legislative provision enables benefit to be paid without the need to, amongst other things, undergo face to face assessments, serve qualifying periods or waiting days, demonstrate care or supervision needs or undertake any work-related activity for the purposes of the respective benefits.
5. An individual with a terminal condition with a life expectancy beyond the period of 6 months is not precluded from applying for any of the five benefits; however, they still need to satisfy the usual qualifying conditions in the benefit and follow the normal application and assessment route.
6. There has been significant lobbying over the last three years, both here and in Great Britain, from charities, clinicians and politicians for changes to be made to the “6 months” criterion to improve access to fast track support for terminally ill people who have a longer life expectancy.
7. On 6 October 2020 the Assembly agreed on a motion that called for the removal of the “6 months” criterion from the special rules for terminal illness. The motion called on the Minister for Communities to immediately bring forward legislation to remove the six month rule, to provide guidance to health professionals and adopt a fairer definition

of terminal illness. It was supported by all of the Executive parties.

8. A judicial review challenge was taken previously around the “6 months” criterion in social security terminal illness provision and whilst the judgment handed down by the High Court here in July 2020 found the provision in place to be discriminatory on ECHR grounds, this was subsequently overturned by the Court of Appeal in August 2021 following an appeal by the Department.
9. Removal of the “6 months” criterion was also included as a recommendation in the Walter Rader Independent Review of the Personal Independence Payment Assessment Process published in June 2018, and was reiterated in the recommendations that emerged from the Second Independent Review by Marie Cavanagh, laid before the Assembly in December 2020.
10. Evaluation and analytical work was undertaken by the Department to consider reform of the current system. Following Executive agreement Minister Hargey announced the way forward on 30 June 2021 by way of Written Ministerial Statement before the Assembly:

http://www.niassembly.gov.uk/globalassets/documents/official-reports/written-ministerial-statements/2020-2021/bv141_wms_dfc_300621.pdf
11. In line with that statement, the change brought forward by this Bill will replace the life expectancy timeframe of “6 months” with “12 months” in the definition of “terminally ill” in the relevant primary and secondary legislation governing each of the five social security benefits.
12. This reform will open up the scope of the current system to enable more terminally ill people to qualify for fast track access to the relevant benefits.

CONSULTATION

13. From July 2019 the Department worked alongside the Department for Work and Pensions (DWP) in Great Britain to undertake an evaluation of terminal illness provision. The views of local claimants, charities and clinicians were gathered as part of this work:
 - A stakeholder event was held by the Department in December 2019 to capture feedback from local medical organisations and charities;
 - The experiences of clinicians were gathered in relation to the special rules process through an online survey (completed February 2020);
 - Research work was conducted with Departmental staff who process special rules applications (March 2020); and
 - Evidence was gathered directly from people who have first-hand experience of the special rules process (conducted in summer 2020 remotely due to the

COVID-19 pandemic).

14. The evaluation findings report can be found at:

<https://www.gov.uk/government/publications/findings-from-the-evaluation-of-the-special-rules-for-terminal-illness-process/findings-from-the-evaluation-of-the-special-rules-for-terminal-illness-process>

OPTIONS CONSIDERED

15. The option of maintaining the status quo and doing nothing to reform the life expectancy timeframe would not address issues highlighted with the current system through the evaluation work.
16. Evidence gathered as part of the wider evaluation work indicated better alignment between the welfare and health systems would be welcomed. Therefore the preferred option to change the life expectancy timeframe criterion to “12 months” aligns more closely with that used by the Health Service here and General Medical Council for the purposes of “end of life” care.
17. Different timeframe options were ruled out at initial consideration stage due to the difficulty associated with clinicians being able to give an accurate prognosis with longer timeframes. Options based on health condition were also ruled out as they could create a hierarchy with a risk of challenge on ECHR grounds. No data existed to enable analytical work to be undertaken around a clinical based approach (with no timeframe). In the announcement made by the Minister on the way forward, it was noted that international best practice would be monitored and that there would be the option of looking further into the feasibility of a clinical led approach in the longer term.

COMMENTARY ON CLAUSES

Clause 1: Special rules to apply where death expected within 12 months

Subsection (2) amends the life expectancy timeframe to 12 months in the definitions of “terminally ill” which are used for the purposes of fast track access to AA, DLA, PIP, ESA and UC. Subsection (2) also contain amendments to enable the new timeframe to apply for the purposes of provisions in decisions and appeals legislation and those relating to passporting advantages, such as premia and disregards, in certain income-related benefits.

Subsections (3) and (4) make amendments to the Social Security Contributions and Benefits (Northern Ireland) Act 1992 to enable the modified version of the prospective test in DLA to apply where death is expected within 12 months.

Subsection (5) adds wording to the Social Security (Disability Living Allowance) Regulations (Northern Ireland) 1992 so that the amended “terminally ill” definition can apply for the purposes of these Regulations.

Subsection (6) updates an older reference to the definition of “terminally ill” in the Social Security (Attendance Allowance) Regulations (Northern Ireland) 1992 with the current one that applies to attendance allowance claimants.

Subsection (8) ensures that the amendments made by the Bill do not apply for the purposes of the Individual Savings Account Regulations 1998 and the Child Trust Funds Regulations 2004. Certain provisions within those Regulations include reference to a “terminally ill” definition used in social security legislation. As those Regulations extend to the entire UK and deal with income tax and child trust funds which are excepted matters, it is considered that changing them is likely to fall outside the competency of the Assembly.

Clause 2: Consequential provision

Clause 2 allows the Department to make by regulations any consequential provision necessary to give full effect to the Bill. Regulations which amend, revoke or repeal any primary legislation cannot come into operation unless and until approved by the Assembly.

Clause 3: Commencement and short title

Clause 3 makes provision about the commencement of the provisions in the Bill and the short title of the Bill.

FINANCIAL EFFECTS OF THE BILL

18. 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 in Great Britain, unless the Executive and Assembly determine otherwise, taking into account any financial and other implications arising from any such deviation.
19. The additional social security benefits cost of moving to the “12 months” model in Northern Ireland is estimated between £1.0m - £4.4m for 2022-23 with an estimated central cost of £2.3m. DWP has announced similar changes to provisions for Great Britain once parliamentary time allows. As the Department plans to bring forward the legislative changes in this Assembly mandate ahead of DWP, Treasury have agreed that any additional expenditure here in advance of a change by DWP would fall to the Executive’s Departmental Expenditure Limits (DEL) Budget. When the corresponding change by DWP comes into operation then the additional expenditure would revert to Treasury funded Annual Managed Expenditure (AME). The Department has bid for the necessary funding as part of the Executive’s Budget 2022-25 Exercise.
20. No material impact is anticipated on public sector manpower.

HUMAN RIGHTS ISSUES

21. The provisions of this Bill are compatible with the Convention on Human Rights.

EQUALITY IMPACT ASSESSMENT

22. In accordance with its duty under section 75 of the Northern Ireland Act 1998, to have due regard to the need to promote equality of opportunity and good relations, the Department conducted a screening exercise on its proposed reform and no adverse impacts are anticipated for any section 75 group.

SUMMARY OF THE REGULATORY IMPACT ASSESSMENT

23. No Regulatory Impact Assessment has been carried out as the amendments brought forward in this Bill will have no impact in terms of costs on business, charities, voluntary bodies or social enterprise organisations.

DATA PROTECTION IMPACT ASSESSMENT/DATA PROTECTION BY DESIGN

24. The changes brought forward in this Bill do not impose any new data gathering/processing requirements. As such a data protection impact assessment is not required.

RURAL NEEDS IMPACT ASSESSMENT

25. A Rural Needs Impact Assessment has been carried out. It noted that there would be no difference in the impact of this reform between people living in urban or rural areas.

LEGISLATIVE COMPETENCE

26. At Introduction the Minister for Communities had made the following statement under section 9 of the Northern Ireland Act 1998:

“In my view the Social Security (Terminal Illness) Bill would be within the legislative competence of the Northern Ireland Assembly.”