

## **Health and Social Care Alliance Scotland (the ALLIANCE)**

**Response: Social Security Administration and Tribunal Membership (Scotland) Bill – Social Security Committee call for evidence**

14 May 2020

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The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 2,900 members including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards and Health and Social Care Partnerships are associate members.

The ALLIANCE's vision is for a Scotland where people who are disabled or living with long term conditions and unpaid carers have a strong voice and enjoy their right to live well.

### **1) Consultation and Engagement**

**Have you engaged with the Scottish Government on the issues address in this Bill? If so, how have you been engaged with the Government?**

The ALLIANCE was a named supporter of briefings coordinated by Marie Curie Scotland and MND Scotland<sup>1</sup> which called for an amendment to the Social Security (Scotland) Bill to ensure that the definition of terminal illness be extended.

The ALLIANCE was also a member of the working group set up to develop guidance for a new definition of terminal illness.

**Are you content with the expedited timetable for this legislation?**

Yes.

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<sup>1</sup> <https://www.alliance-scotland.org.uk/blog/resources/terminal-illness-briefing-social-security-scotland-bill-stage-1/marie-curie-mnd-scotland-briefing-terminal-illness-definition-for-social-security-stage-one-debate-2/>

## 2) Terminal Illness

**Did you engage with the Scottish Government on the terminal illness amendment to the Social Security (Scotland) Bill in 2018, and if so, whether at the time they were content with the term ‘medical practitioner’, and if so, what has changed?**

As noted above, the ALLIANCE was a named supporter of briefings coordinated by Marie Curie Scotland and MND Scotland which called for an amendment to the Social Security (Scotland) Bill to ensure that the definition of terminal illness be extended.

The briefings<sup>2</sup> noted that, to be fast tracked for social security support, terminally ill people must have had a Department for Work and Pensions (DWP) DS1500 form completed by their clinician, who must have confirmed s/he had just 6 months or less to live. However, 6 months life expectancy has *no* clinical meaning in most terminal illnesses. The briefings concluded that a terminal illness definition based on need, rather than life expectancy, should be introduced to support the administration of social security benefits in Scotland.

The Scottish Government adopted a version of this suggestion at Stage 3 of the Bill’s progress through the Scottish Parliament, welcomed by our members, however, it contained the caveat that forms could only be signed off by “medical practitioner” defined elsewhere as Doctors, rather than nurses. Due to the timescale at which the amendment was drafted and submitted to Parliament we did not feel that the consequences of this proposal received the consideration they deserved. We understand from our members that in discussion with the Scottish Government, the decision to exclude nurses was an oversight on their part and that it had always been their intention to include nurses.

We believe that the spirit with which the amendment was brought forward by our members aimed to ensure everyone with terminal illness was enabled to receive quick, timely access to social security entitlements. We are concerned that without the proposed change in this new Bill, this would not have been possible.

**What training and skills should nurses have in order to act under the terminal illness provisions?**

Registered Nurses can act as a link between different types of health and care support and services and are often the closest professional to the individual receiving palliative care support and/or their unpaid carers, families, and friends. This

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<sup>2</sup> <https://www.alliance-scotland.org.uk/blog/resources/terminal-illness-briefing-social-security-scotland-bill-stage-1/marie-curie-mnd-scotland-briefing-terminal-illness-definition-for-social-security-stage-one-debate-2/>

type of connection can contribute significantly to the quality of care and person centredness experienced by an individual living with terminal illness. Registered Nurses are trained and employed to do some element of evaluation and assessment of condition and recording of symptoms. The Clinical Nurse Specialist roles often employed in a palliative care setting use their skills and expertise in palliative and end of life care to provide physical and emotional support, coordinate care services and to inform and advise people on clinical as well as practical issues, leading to positive patient outcomes. We believe that this professional experience indicates their ability to diagnose terminal illness as defined in the 2018 Act for the purpose of establishing eligibility for disability assistance.

If further reassurance is required by the Scottish Government, we agree with Marie Curie that some form of mandatory training, preferably carried out remotely, may be possible. This would offer them broader information about the nature of the new entitlement and how to use the new rules in practice.

### **Should health professionals other than registered nurses be included in the definition of ‘appropriate healthcare professional’?**

We believe, at this stage, that the suggested amendment to the Act is sufficient, however it may be useful to keep this element of the Act under review for future consideration if other professionals, including Allied Health Professionals and staff working in the third sector, could offer support to enable quicker access to social security entitlements for people living with terminal illness.

We believe that the Scottish Government should ensure that any guidance produced as noted at **Section 7 2, (2B) In defining “appropriate healthcare professional”** should not be overly prescriptive as to define too stringently the relevant skills, training, qualifications and experience. Operating as a Registered Nurse working with an individual should be sufficient as to allow someone to diagnose terminal illness for this purpose.

### **Other comments**

#### **Suspension of payments**

Regulations appear to remove entitlement for children or young people who spend more than 28 days in a care home, residential educational establishment or legal custody.<sup>3</sup> As Citizens Advice Scotland note in their submission to the Committee, this could be achieved by amending the Act to enable entitlement to remain while

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<sup>3</sup> Citizens Advice Scotland response to Scottish Commission on Social Security consultation: The Disability Assistance for Children and Young People (Scotland) Regulations 2020 – January 2020  
[https://www.cas.org.uk/system/files/publications/cas\\_response\\_-\\_dacyp\\_regulations.pdf](https://www.cas.org.uk/system/files/publications/cas_response_-_dacyp_regulations.pdf)

payment is suspended.<sup>4</sup> We would recommend the Bill is used as an opportunity to amend the 2018 Act to make provision for a suspension and resumption of a benefit, rather than removing entitlement.

## **Challenging liability to repay an overpayment in a Tribunal**

As Citizen Advice Scotland note in their submission to the Committee, at Stage 3 of the Social Security (Scotland) Bill's passage through the Scottish Parliament, amendments were considered relating to allowing people to challenge liability to repay a social security overpayment through an appeal to the Tribunal, rather than through the Sheriff Court. Section 68 of the Act (proposed to be replicated for 'top-up' benefits by Section 4 of the Bill) creates a power for Scottish Ministers to make regulations to transfer certain powers in this regard from the Sheriff to the Tribunal.

However, despite consensus around the principle of challenge in a Tribunal in Parliament<sup>5</sup> and subsequently from discussions with stakeholders, regulations have not been brought forward at the time of writing. The Bill may present an opportunity to consider whether it would be appropriate to make an amendment to transfer the powers to the Tribunal in legislation, rather than by regulations.

### **For more information**

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<sup>4</sup> Scrutiny Report on draft regulations: Disability Assistance for Children and Young People (Scotland) Regulations 2020 – Scottish Commission on Social Security, March 2020  
<https://www.gov.scot/binaries/content/documents/govscot/publications/independent-report/2020/03/the-disability-assistance-for-children-and-young-people-scotland-regulations-2020-scrutiny-report-on-draft-regulations/documents/the-disability-assistance-for-children-and-young-people-scotland-regulations-2020-scrutiny-report-on-draft-regulations/the-disability-assistance-for-children-and-young-people-scotland-regulations-2020-scrutiny-report-on-draft-regulations/govscot%3Adocument/FINAL%2BSCoSS%2BReport%2Bon%2Bthe%2Bdraft%2BDACYP%2B%2528S%2529%2BRegs%2B2020.pdf>

<sup>5</sup> Col. 72-76, Official Report, 25 April 2018

<http://www.parliament.scot/parliamentarybusiness/report.aspx?r=11482&mode=pdf>