MND Scotland response

MND Scotland welcomes the opportunity to submit a response to the Health & Sport Committee’s call for evidence on the Health and Care (Staffing) (Scotland) Bill. In this response we have highlighted the need to continue to deliver specialist care to people with Motor Neurone Disease in Scotland.

For this consultation, we are limiting our responses to Part 3 of the Bill as we know that care provision is a real concern to many people affected by MND. Our recent independent survey of people affected by MND found that many experience delays with having their care package put in place and almost no-one with the illness receives any overnight care. When asked what good social care would look like to people affected by MND, the key things highlighted were: having regular carers (the same person each visit); a full care package more quickly; more regular visits; and, longer visits.

Consultation questions:

1. Do you think that the Bill will achieve its policy objectives?

It could but the Bill does not have sufficient detail to indicate how likely this is. The guiding principles are good and overall the sentiments of the Bill are well-intentioned. If done well, it could help stabilise the workforce in key areas of Health and Social Care. However, we believe that the Scottish Government should listen to the ongoing concerns of the sector. It is crucial that the Scottish Government work with others to resolve problems relating to recruitment and retention of health and social care staff. This is key to how the policy objectives can be achieved.

2. Key strengths of Part 3 of the Bill

At 6(1) the needs of the service user are most prominent.

7 – Training of staff seems positive.

8 – Similarly, Ministerial guidance on staffing is also positive but we hope that 8(2)(b) will include third sector representatives.

3. Key weakness of Part 3 of the Bill

Given the strength of 6(1), it is disappointing that the needs and numbers of service users only feature at (d) and (e) on the list.
82A (1) what is meant by ‘staffing methods’ is not clear to us.

82A (5) Again, we are disappointed that the needs of service users are listed as low as (e) here. In addition, at (f) and (g) ‘comments’ seems very vague. How can it be ensured that comments picked out are meaningful, significant and representative? Perhaps ‘any concerns’ highlighted by service users and their families as well as staff would be more helpful.

Is there anything you would change in the Bill?

There should be more reference to families and informal carers throughout the Bill, alongside reference to service users.

There is a lot of reference to ‘must have regard to…’ in the Bill. We feel that this is not strong enough and could amount to little in practice if resources for care services are not sufficient to provide the care needed.

4. What differences, not covered above, might the Bill make?

The Bill alone will not ensure staffing service levels are safe. Strong service user and informal carer focused guidance is essential. We also recommend that the findings from the 2016 Dying to Care report are immediately implemented.

Dying to Care report 2016

A series of recommendations to help improve care for people with all terminal and chronic conditions was highlighted in the Dying to Care report1. The report was jointly published by Marie Curie, Hospice UK, MND Scotland and The Association of Palliative Care Social Workers in 2016.

The report includes a series of recommendations relating to the improvement of social care, and the professionalisation of the health and social care workforce.

The recommendations for social care include ensuring:

- there are no unnecessary delays between assessment and provision of social care support for people living with a terminal illness and their carers
- respite care can be planned in advance, but is also accessible during crisis points in someone’s illness
- that services are in a position to change social care packages quickly to respond to a crisis or deterioration of the patient or the carer or if the person’s wishes change.

The recommendations for training social care professionals include:

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- palliative care and bereavement training, as a mandatory part of education across all social care curriculums including social work degrees, specialisms such as occupational therapy and physiotherapy, and core training for all care at home and nursing and care home staff
- communication training for health and social care staff to support them with sensitive conversations about death and dying, as well as anticipatory care planning to ensure a person’s preferences, choices and wishes are accurately recorded.

We believe that these key recommendations can be achieved if appropriate and careful workforce planning is carried out by both the NHS and Care organisations. This will enable staff to find the adequate time for training and learning opportunities as part of their continuous professional development.

**Delayed Discharge**

People with MND will be required to have, in most cases, a short stay in hospital following a procedure. This could include being fitted with a feeding tube, also known as a Percutaneous endoscopic gastrostomy (PEG) or a Non-invasive ventilation (NIV) to assist with respiratory problems.

As well as having safe and effective staffing levels to oversee these procedures, it is essential that there are appropriately trained staff to enable the safe discharge of a patient with MND. Recently, we have seen an increasing number of cases where a patient with MND is ready to leave hospital but there are insufficient resources in the community to enable them to return home. Being stuck in a hospital ward, unable to return home, can be very distressing for a person with MND and their family.

In a recent case, the health of one lady with MND deteriorated very quickly when a suitable care package could not be sourced. After weeks of waiting, and with deteriorating health, she never returned home. She died in hospital while waiting for a care package. While there were no complaints about the high quality care received and the compassion of the NHS staff, it was not an appropriate setting for her. We need to ensure cases like these do not become the norm. We need to ensure that people have the choice to die at home, surrounded by their loved ones.

In part, cases as described above, are due to shortages in the social care sector. MND is a progressive condition and social care staff need to be adequately trained so that people with MND can be cared for at home. Ensuring that staff receive expert training can help upskill the workforce and could be key to retaining staff. This is why it is essential that current problems with recruitment and retention are addressed. We would recommend the government works closely with Scottish Care, the Care Inspectorate and others to address the pressures which currently exist within the social care sector.

**The Social Care workforce and Brexit**

As with other sectors in the UK, there is concern that the impact of the UK leaving the European Union (EU) could have a detrimental effect on the health and social care workforce. Last year, we responded to a survey by The Alliance on the impact
of leaving the EU. In our response, we noted that retention and recruitment problems in social care could be exacerbated\(^2\) by retraction from the freedom of movement utilised by many social care staff at present. This was highlighted in The Alliance’s response to the Health and Sport Committee’s Inquiry into the impact of leaving with EU\(^3\). It is important to reiterate the findings of this inquiry as many of the concerns overlap with the challenges relating to recruitment and retention of staff.

**About MND**

Motor Neurone Disease (MND) is a rapidly progressing terminal illness, which stops signals from the brain reaching the muscles. This may cause someone to lose the ability to walk, talk, eat, drink or breathe unaided. There is currently no cure or effective treatment for MND and the average life expectancy from diagnosis is just 20 months.

On average almost 200 people are diagnosed each year in Scotland, 53% die within one year of diagnosis and 6.5% live for more than 5 years after diagnosis.* There are over 450 people in Scotland currently living with MND.

*data from the Scottish MND Register 2015 and 2016.

**About MND Scotland**

MND Scotland is the only charity in Scotland supporting people affected by Motor Neurone Disease, as well as funding vital research to find a cure.

We campaign and raise awareness to make the lives of people affected by Motor Neurone Disease better, and provide hope for a world without MND.

Our campaigns change laws, change attitudes, and fight for better services and care for everyone with MND.

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\(^2\) [http://www.parliament.scot/S5_HealthandSportCommittee/Inquiries/BREX010_the_ALLIANCE.pdf](http://www.parliament.scot/S5_HealthandSportCommittee/Inquiries/BREX010_the_ALLIANCE.pdf)