HSCWB21 Motor Neurone Disease (MND) Association,

Senedd Cymru | Welsh Parliament

Y Pwyllgor Iechyd a Gofal Cymdeithasol | Health and Social Care Committee

Bil Iechyd a Gofal Cymdeithasol (Cymru) | Health and Social Care (Wales) Bill

Ymateb gan Motor Neurone Disease (MND) Association, | **Evidence from** Motor Neurone Disease (MND) Association,

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General principles of the Bill

1. What are your views on the general principles of the Health and Social Care (Wales) Bill?

(we would be grateful if you could keep your answer to around 500 words)

We broadly welcome the principles contained within the Bill and we do believe there is a need for such legislation to deliver the state policy intentions.

However, we are concerned about the implementation of these changes which will be detailed below.

2. Is there a need for legislation to deliver the Welsh Government's stated policy intention?

Yes

Please outline your reasons for your answer to question 2

(we would be grateful if you could keep your answer to around 500 words)

3. What are your views on Part 1, Chapter 1 of the Bill (sections 1-13), which makes provision intended to restrict the extraction of profit by providers of children's care home services, secure accommodation services and fostering services

(we would be grateful if you could keep your answer to around 500 words)

4. What are your views on Part 1, Chapter 2 of the Bill (sections 14-22 and schedule 1), which makes a number of amendments in relation to social care services, social care workers and local authority social services, intended to ensure that the 2014 and 2016 Acts can operate fully and effectively

(we would be grateful if you could keep your answer to around 500 words)

5. What are your views on Part 2 of the Bill (sections 23-26 and schedule 2), which relates to health care, and makes amendments to the National Health Service (Wales) Act 2006 in order to enable the introduction of direct payments within NHS Continuing Healthcare

(we would be grateful if you could keep your answer to around 500 words)

We welcome the amendments to enable the introduction of direct payments within NHS Continuing Healthcare.

Motor Neurone Disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It kills a third of people within a year and more than 50% of people within two years. MND is a lifelong disease for which there is no cure.

Due to the complex and rapidly progressing nature of the disease, the care and support needs of those living with MND are highly variable and continually changing. This means that those living with MND require care which is both specialist and flexible. We believe that direct payments allow those living with MND to source their own specialist care providers who will be able to deal with their complex needs.

However, in order for this change to be impactful, it must come with adequate support and signposting, a clear plan to address issues within the social care workforce and a review of the level of direct payments. Further information on this will be detailed below.

6. What are your views on Part 3 of the Bill (sections 27-30) which contains a number of general provisions, including in relation to regulations, interpretation, consequential and transitional provisions, and coming into force provisions

(we would be grateful if you could keep your answer to around 500 words)

Implementation and impact of the Bill

7. Are there any potential barriers to the implementation of the Bill's provisions? If so, what are they, and are they adequately taken into account in the Bill and the accompanying Explanatory Memorandum and Regulatory Impact Assessment?

(we would be grateful if you could keep your answer to around 500 words)

As outlined above, we have three main ongoing concerns that will affect implementation of the Bill's provisions surrounding direct payments for continuing health care (CHC):

1) Adequate support

We are concerned that not enough information is contained within the Bill to communicate changes in legislation and processes to people in Wales at present. We note the discussion during the evidence session with the Cabinet Secretary for Health and Social Care surrounding the changes contained within the Bill, most notably the need for better help during the transition process, particularly for those that are new to CHC. We are aware there are many concerns around the move to CHC and many challenges faced by people living with MND and their carers in accessing CHC and particular issues with the decision support tool, which is limited and does not always support effective communication and decision making. While we welcome the Cabinet Secretary's reassurance that support will be provided on a Hub basis, we believe more detail and more proactive, targeted support is needed. We also urge Welsh Government to ensure that those who do not wish to use direct payments may continue to have the option of care arranged on their behalf.

2) Social care workforce

The move towards more flexibility with direct payments will not be a positive change unless it is accompanied by a sustainably resourced social care workforce that is readily available to deliver the support needed. Direct payments are of no benefit in areas where care staff with the required skills and training are not available.

We welcome the recent publication of the Welsh Government's Social care workforce delivery plan 2024-2027. We do believe range of measures outlined will improve wellbeing and retention within the social care workforce. However, the plan does not contain information on how to increase rather than simply maintain current levels of staff within the workforce and lacks any concrete targets to deliver effective change in the short term. We must be clear that our concerns around staffing levels are impacting people living with MND currently and more ambitious, more rapid guarantees are needed from Welsh Government to improve the quality of life for those living with MND in Wales.

3) Level of payments

In a previous response, we highlighted the need for direct payments to be set at a level that allows people living with complex conditions such as MND to access the specialist care they need. Generic care provision is inadequate for people living with MND as they commonly need specialist expertise and staff with specialist training to support with equipment such as artificial respiration, communications equipment, and mobility equipment. Such specialist care comes at a much higher cost than generic support packages provide, and direct payments must be set at a level corresponding to this level of need.

We are also aware of discrepancies in the approach in implementing CHC between different local health boards (LHBs) in Wales. For example, in North Wales, those requiring riser recliners cannot access them via local authorities and have to access via the NHS and in some cases the LHB will only provide a wheelchair. It is vital that the level of payment is the same across Wales, so that people living with MND and their carers have equal access to support.

8. Are any unintended consequences likely to arise from the Bill?

(we would be grateful if you could keep your answer to around 500 words)

9. What are your views on the appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 5 of Part 1 of the Explanatory Memorandum?)

(we would be grateful if you could keep your answer to around 500 words)

10. What are your views on the Welsh Government's assessment of the financial and other impacts of the Bill as set out in Part 2 of the Explanatory Memorandum?

(we would be grateful if you could keep your answer to around 500 words)

While we appreciate there may be some upfront costs during implementation, we agree that these will be offset by a reduction in outturn costs as set out in the Explanatory Memorandum.

We believe the introduction of direct payments could result in cost saving for Welsh Government as sourcing specialised care individually may be less costly than social care provision. As no two cases of MND are the same, direct payments would allow for a more personalised care package which may, in turn, lead to both less surplus expenditure and more rapid delivery than traditionally commissioned CHC.

11. What are your views on the Welsh Government's integrated impact assessments (set out in Part 2 of the Explanatory Memorandum), including the Children's Rights Impact Assessment

(we would be grateful if you could keep your answer to around 500 words)

Development of the policy and legislative proposals

12. What are your views on the approach taken by the Welsh Government to the development of the policy and legislative proposals reflected in the Bill.

Among any other issues, please consider in particular the approach to engaging and consulting with stakeholders

(we would be grateful if you could keep your answer to around 500 words)

Any other issues

13. Are there any other issues that you would like to raise about the Bill, the accompanying Explanatory Memorandum and Regulatory Impact Assessment, or any related matters?

(we would be grateful if you could keep your answer to around 500 words)