

HSCWB37

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 Anabledd Cymru | Evidence from Disability Wales

Please use this template to draft your responses to submit via the online consultation form.

Evidence from: Disability Wales

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You do not need to answer every question, only those on which you wish to share information or have a view.

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)

Our consultation response will focus primarily on the proposals on adult health and social care. We agree with the general principles of the Health and Social Care (Wales) Bill and are glad to see the Welsh Government enacting direct payments which have been campaigned for by disabled people for many years. However, we are concerned at the lack of reference to the United Nations Convention on the Rights of Disabled People. Although there have been commitments by the Welsh Government to the Convention, it is not currently incorporated into Welsh law. We believe that the framework for disability rights set out in the Convention is vital for the proper implementation of the changes suggested, particularly regarding continuing healthcare. Disability Wales would recommend that the Bill is updated to reaffirm and reflect the Welsh Government's commitment to the Convention on the Rights of Disabled People.

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

☒ Yes

☐ No

☐ Don't know

☐ Don't have a view

Please outline your reasons for your answer to question 2

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

Yes currently Welsh Government legislation does not allow for direct payments under continuing health care. This is an issue which disabled people have campaigned on for many years. Direct payments allow a level of flexibility that is not available under other systems. Through this the disabled person can fine tune the care they are receiving to their circumstances and allows them the ability to hire their own personal assistants, often a role which requires a particular level of intimacy and requires personalities to mesh well. We do not believe that the benefits of this policy could take place without specific legislation.

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)

No comment.

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)

No comment.

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 are in favour of the introduction of direct payments within NHS Continuing Healthcare. We have seen examples from this working in the NHS England and believe that this would provide much needed flexibility to CHC in Wales. Direct payments are particularly useful as they provide greater autonomy and control over the care that a disabled person can access. This is particularly important for support such as the hiring of personal assistants, in which the disabled person feeling comfortable around that individual, getting along with and establishing a good working relationship with is essential for successful care. We have seen incidences of disabled people not accepting continuing healthcare, to not lose their direct payments. Not having direct payments in continuing healthcare sets up a two-tier system in which disabled people who receive this care through their local authorities have access to more autonomy and control over their care than those who receive it from their health board.

The introduction of direct payments into continuing healthcare has been the subject of campaigning from disabled people in Wales for years. Our only concern with how it is set out in the Bill is the proposed timeline, two years is a long wait for those who have been either refused continuing healthcare to keep direct payments, or who have been moved to continuing healthcare and wish to have access to direct payments. We would seek clarity from the Welsh Government on the reasons for this timeline to give assurances to those who are currently waiting for this legislation. We would also like to see more information on how this will be monitored, later in this document we will raise criticisms of the lack of direct consultation with disabled people in this Bill. There has been criticisms raised by organisations like People Places Lives on a lack of data on take-up and experiences of direct payments in Wales, we would recommend more specific provisions be made on ensuring that data is collected and the implementation of direct payments under continuing healthcare is monitored co-productively with disabled people.

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)

No comment

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)

None that we can identify.

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)

We are concerned that an unintended consequence would be a shift to force people to move to direct payments who do not want to or for whom they would not be suitable. Disability Wales wants to make our position extremely clear, we believe that it is important that direct payments under continuing healthcare is an option for disabled people, but with the acknowledgement that they do not work for all. The responsibility of becoming an employer and hiring your own support is not suitable for all and some people prefer the other system. We are concerned that if this is interpreted as disabled people should be on direct payments under continuing healthcare that for those where direct payments are not suitable, they would have less access to the appropriate care for them. These issues would be rectified by clear guidelines that this is not an appropriate approach for all and to ensure that the disabled person has enough information to be able to make an informed decision about the right approach for them.

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)

We believe that these are appropriate powers and that keeping this in line with current legislation.

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)

No comment.

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)

No comment.

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)

We were disappointed in the approach taken to the development of these policies and legislative proposals. We do not believe that enough engagement was done with disabled people prior-to the publication of this report. Disability Wales was not informed of the proposals until a few days before it's publication, other organisations were not given advance notice at all.

Although we are broadly supportive of the proposals, there are gaps that prior engagement with disabled people and disabled people's organisations would have helped address. Particularly we would like to see how the monitoring and implementation of these proposals will include disabled people with lived experience of the system.

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)

No comment.
