

Proposed changes to legislation on social care and continuing health care

Consultation Response Form

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Organisation (if applicable): Learning Disability Wales

Questions on Chapter 1: Eliminating profit from the care of children looked after

Question 1.1: Do you think that introducing provision in legislation that only allows 'not-for-profit' providers to register with CIW will support delivery of the Programme for Government commitment to eliminate profit from the care of children looked after?

We are very happy to see Welsh Government moving towards removing private profit from provision for children's services. We would like to encourage Welsh Government to explore the possibility of also doing so for adult social care services.

The Policy Proposal makes a convincing case for why private profit has no place in the provision of children's services. You write that:

Our aim is to ensure that public money invested in the care of children looked after does not profit individuals or corporate entities, but instead is spent on children's services to deliver better experiences and outcomes for children and young people, addressing service development and improvement and further professional development for staff (page 3)

You also state that up to 20% of the money put into residential care for children is lost to private profit. We would like to know what the equivalent number is for adult services and ask Welsh Government to explore the feasibility to come to similar resolutions in terms of addressing the issue.

While we do not have up-to-date information for Wales, we note that a 2016 report from the *Centre for Health and Public Interest* on the impact that privatisation had had on the quality of care in England found that "Both the quality of care in adult social care and the terms and conditions of the workforce have declined over the past two decades as a result of privatisation. The report also shows that turnover rates are higher, and rates of pay considerably lower, in the private care sector than in the public sector.

In addition, 41% of community-based adult social care services, hospice services and residential social care services inspected by the Care Quality Commission since October 2014 were found to be inadequate or requiring improvement¹". We believe that findings like that may imply a strong case to critically investigate the role of private providers in adult social care in Wales.

Question 1.2: What in your view are the likely impacts of the proposal? You may wish to consider, for example:

- Benefits, and disbenefits;
- Costs (direct and indirect), and savings;
- Impacts upon individuals and groups with protected characteristics;
- Other practical matters such as cross-border issues.

Your views on how positive effects could be increased, or negative effects could be mitigated, would also be welcome.

Please explain your reasoning.

Question 1.6: Are there any issues in relation to transition for children looked after, local authorities and service providers you would like to draw our attention to?

A significant amount of work will need to be done to ensure that those individuals currently being supported by for-profit providers are successfully transitioned to new providers with continuity of care and minimal disruption to their daily lives. There is a risk that some for-profit providers might suffer significant financial difficulties if this goes ahead and this could lead to some going into liquidation or simply withdrawing services overnight, potentially leaving vulnerable people with no care and support. It is essential that contingency plans are in place to avoid people ending up being transferred to expensive out-of-area placements away from their families, friends and communities due to a lack of alternative, good quality local provision.

Question 1.7: What are your views on the issuing of guidance to support the implementation of the primary legislation?

It is important that all guidance around this is produced with accessibility in mind. We urge Welsh Government to take accessibility more seriously, given the inaccessibility of this process. The proposals in this document have a clear and important impact on people with a learning disability as well as young people. As such it is extremely disappointing that this consultation was not conducted in a more accessible way. There was no easy read material for this consultation available originally. An easy read summary was published approximately two weeks before the submission date. As it was only a summary, the easy read document was too vague for anyone to develop a real understanding of the

proposals and be able to make informed decisions about the content. There was also no easy read questionnaire available.

It is also worth noting that the proposal itself was not written with accessibility in mind. It would have been good to give the document another edit to make sure things are phrased clearly and questions are asked in the most straightforward way possible.

Questions on Chapter 2: Introducing direct payments for Continuing NHS healthcare

Question 2.1: We have outlined our proposals to introduce further voice and control for adults receiving Continuing Health Care (CHC) in Wales. Do you agree or disagree with these proposals? Please explain your reasoning.

We support the implementation of direct payments for health budgets as they are something disabled campaigners have been asking for a long time. People with a learning disability often do not feel like they have control over their lives. We also know that many disabled people do not feel they have the control over their medical treatment that they should. Giving people more control over their medical decisions is a good step towards this.

Question 2.2: What in your view are the likely impacts of the proposal?

You may wish to consider, for example:

- Benefits, and disbenefits;
- Costs (direct and indirect), and savings;
- Impacts upon individuals and groups with protected characteristics;
- Other practical matters such as cross-border issues or transition to the new arrangements.

Your views on how positive effects could be increased, or negative effects could be mitigated, would also be welcome.

Please explain your reasoning.

Our concern however is that these changes could possibly disadvantage people with a learning disability by placing a disproportionate administrative burden on them.

You give the reason for wanting to implement personal health budgets as enabling greater voice and control for adults and moving towards more integrated, person centred provision within health and social care. You write that you are also

promoting fairness and continuity to care is important. We agree that all of these are important goals and that Personal Health Budgets can play an important part of addressing these issues.

However, we are concerned that in times of austerity and systematic underfunding of the NHS people may choose to accept Personal Health Budgets because they cannot get the care they need. It is important that NHS funding is protected and people's choices and autonomy are given the support they need.

We are concerned that people with a learning disability might feel pressured to take on health budgets because the care they get otherwise is not adequate. They then might find that they struggle with the administrative burden that comes with health budgets. It is important that people with a learning disability and family carers receive substantial support in using the budgets if they chose them.

Support also needs to be put in place to make sure people with a learning disability who chose the Personal Health Budgets get support when something goes wrong with the services they are buying. Measures need to be put in place to make sure predatory providers do not take advantage of people using the budgets.