



Ymateb i Ymgynghoriad / Consultation Response

Date / Dyddiad: 01/08/19

Subject / Pwnc: Health, Social Care and Sport Committee Stage 1 Scrutiny of the Health and Social Care (Quality and Engagement) (Wales) Bill

Background information about the Children's Commissioner for Wales

The Children's Commissioner for Wales' principal aim is to safeguard and promote the rights and welfare of children. In exercising their functions, the Commissioner must have regard to the United Nations Convention on the Rights of the Child (UNCRC). The Commissioner's remit covers all areas of the devolved powers of the National Assembly for Wales that affect children's rights and welfare.

The UNCRC is an international human rights treaty that applies to all children and young people up to the age of 18. The Welsh Government has adopted the UNCRC as the basis of all policy making for children and young people and the Rights of Children and Young Persons (Wales) Measure 2011 places a duty on Welsh Ministers, in exercising their functions, to have 'due regard' to the UNCRC.

This response is not confidential.

Key messages

- This Bill will align some of the inconsistencies across health and social care and I welcome this move towards more seamless health and social care.
- I am pleased that a national Citizen Voice Body is to be established, and that under 18s will be able to access support in making complaints about the NHS. However, there is not enough instruction within this Bill to ensure that children and young people are represented, included in, engaged in, and coproduce the work of the new Citizen Voice Body.
- This Bill is a missed opportunity to clarify and formalise an advocacy offer for children and young people across health and social care.

Introduction

The principle of aligning the duties of health and social care as this Bill sets out is welcome. The Bill provides some response to the Parliamentary Review¹ which called for person-centred and seamless services, and is in line with the ambitions of the Welsh Government's 10 year strategy document, *A Healthier Wales*².

Broadly, this Bill will provide the framework for a more cohesive health and social care system for the service user, which is so desperately needed. Casework undertaken by my investigation and advice team, and conversations with professionals, provide evidence of situations where children and young people have 'fallen through the cracks', and have been left without the care and support they need, with health and social services arguing over their heads over who is responsible for their care. One example of this has been a young person who displayed very concerning behavioural and mental health issues and who, following an incident involving aggressive behaviour and the involvement of police, was kept on unsuitable adult wards and supervised by agency staff for weeks. There has been some disagreement as to whether health or social care services should have primary responsibility for their care. The young person has been acutely aware of this and unhappy about their own level of involvement in the decision-making process.

¹ <https://gweddill.gov.wales/docs/dhss/publications/180116reviewen.pdf>

² <https://gov.wales/sites/default/files/publications/2019-04/a-healthier-wales-our-plan-for-health-and-social-care.pdf>

This case study is detailed alongside others in a [letter](#) to the Chair of the Children, Young People and Education Committee. This is not an isolated case, as demonstrated in this letter.

Importantly, the new Citizen Voice Body proposed in the Bill *could* provide a forum for engagement, participation and coproduction with young people which is missing under the current structure of Community Health Councils (CHCs). However, as there is no detail of how the Citizen Voice Body will be ensured to be representative of the population, it is difficult to comment on the potential effectiveness of the Body.

Neither the Bill itself nor the explanatory memorandum provide a clear direction that children and young people will now be able to contribute to the work of the Citizen Voice Body, and gives little detail on children and young people's access to complaints advice and assistance. Although I assume the use of 'any individual' to include children and young people, I would like to see this made more explicit within the Bill, as it is vitally important that children and young people feel empowered to engage with and use the services of the new Body. In my experience, public bodies do not always consider the role of under 18s when planning patient or citizen involvement.

Advocacy for Children and Young People in Health and Social Care

This Bill presents an opportunity to provide clarity over the position of an advocacy offer for children accessing health services. However, it has failed to take advantage of this opportunity. The offer within this Bill is of a narrow complaints advice and assistance service, and will not be available to all children and young people in Wales (as those who qualify for statutory independent advocacy through their involvement with social services are excluded from this legislation). It is clear to me that children and young people accessing health services who do not qualify for statutory independent advocacy through their involvement with social services, or as a qualifying mental health patient, should be able to access an advocate through this body if their concern relates to health matters.

Ideally, a young person should not have more than one advocate, but this advocate should cover all the needs that young person has across various agencies. I would like to have seen this Bill establish an advocacy service which provided as far as possible advocacy for children and young people which covers both health and social care needs.

I wish to set out a series of outcomes that I would expect Welsh Government to be working towards in relation to advocacy provision across health and social care for children and young people in Wales.

I would expect outcomes across health and social care to include:

- A service which offers face-to-face advocacy to any child or young person who needs it in order to participate in decisions about their own case and understand the treatment that is being offered to them
- A service which offers face-to-face advocacy recognising additional barriers faced by young people, such as language or disability
- Advertisement of advocacy services across health settings used by children and young people, in a child-friendly format
- A service which adheres to the principles of independent professional advocacy
- A service for children and young people who wish to make complaints

It is important to emphasise here that advocacy is not just about complaints, a premise that too often gets lost when discussing provisions for advocacy. This was reflected at my recent Child Health Seminar, attended by representatives of all health boards in Wales, where attendees compiled a list of core principles for advocacy where the need for a holistic advocacy service was emphasised by many. However, Part 4 of the Act as currently drafted is clear that advocacy is provided only in relation to complaints.

Some examples of where children or young people may need an advocate may include:

- When making decisions about transitions to adult services
- When facing a decision about a potential course of treatment
- When their care plan is being developed
- When they hold a different view from their parents or carers
- When their parents or carers are unable or unwilling to facilitate their involvement in decision-making

Advocacy in health settings currently provided is patchy across health boards in Wales, varying from health boards meeting only the statutory provision under Mental Health legislation, providing ad-hoc advocacy provision beyond just mental health, and more established commissioned advocacy services.

There have also been historic issues with advocacy in social care, with different local authorities commissioning different levels of advocacy provision as there is no consistency in commissioning practice across Wales. This has since been tackled with the introduction of the Social Services and Well-being (Wales) Act 2014 and the establishment of a National Approach to Statutory Advocacy across Wales, including an Active Offer of advocacy services. This was a lengthy piece of work with local authorities, the Government and third sector stakeholders including my office, to ensure that all local authorities were commissioning and offering the same level of advocacy and support to the young people receiving care and support services, so that any relevant young people could have the support they need to navigate the system and fully participate in meetings and decisions.

I am concerned that the provision of advocacy in health services has neither the infrastructure nor the quality that is needed as things currently stand.

There are also concerns about the reporting and accountability of advocacy services in health. There is currently no reliable picture of numbers accessing advocacy provision, or outcomes of the use of advocacy services, in health settings. The Active Offer of advocacy in social care is required to be recorded in a child's care plan review by their Independent Reviewing Officer, for example. The National Approach to Statutory Advocacy also includes reporting requirements on the take up of the active offer and subsequent advocacy provision.

In addition, advocacy will be a regulated service under the Regulation and Inspection of Social Care (Wales) Act, to ensure that those providing the service are suitably qualified and experienced, and that other quality standards including safeguarding matters, are upheld.

For children and young people who require advocacy but do not qualify for statutory provision, the option they are likely to be presented with currently is the *Putting Things Right* process, where children are advised to contact the MEIC service. This can be an important phone line / online service for children and young people, but it does not provide face-to-face advocacy support.

I suggest that the government should properly consider whether a jointly commissioned health and social care advocacy offer could be organised regionally through the Regional Partnership Boards; or whether separate work streams in health and social care work towards effective active offers of advocacy being available to children and young people accessing either or both services.

It is also not clear to me how the arrangements for resolving concerns and appeals in the Additional Learning Needs and Education Tribunal (Wales) Act fit with the arrangements under this Bill.

Duty of Quality and Duty of Candour

I welcome the introduction of a Duty of Quality, and a Duty of Candour, within this Bill. In my response³ to the white paper *Services Fit for the Future: Quality and Governance in Health and Care in Wales*⁴, I called for the duty of quality to ensure that the rights and needs of the population, including children and young people, are prioritised; and that mechanisms are in place to ensure oversight and accountability to such a duty. I am concerned that the Bill in its current form gives little detail of how both the duty of quality and the duty of candour elements will be properly monitored, other than through the annual reporting mechanism from Ministers, and Health Boards and Trusts. However, I am pleased that the scope of this annual report function appears to be wide-ranging, and is an improvement on the previous CHC system.

With respect to the Duty of Candour, I welcome the Bill's objective of avoiding the defensive, 'closing ranks' approach when things go wrong. There is currently little detail, however, on how the Duties of Candour in health and social care will align in practice. I am also concerned that there is currently a question mark over the definition of the 'more than minimal harm' threshold. While I am aware that the explanatory memorandum outlines the process for producing guidance on this definition, it is important that this threshold is compatible with the social care Duty.

Citizen Voice Body

In my response to the White Paper, I called for developments to strengthen the voice of the citizen which 'must include methods to engage children and young people to uphold their right to do just this'.

³ <https://gov.wales/sites/default/files/consultations/2018-02/180226summary-of-responses.pdf>

⁴ <https://gov.wales/sites/default/files/consultations/2018-01/170628consultationen.pdf>

I am concerned that the legislation does not set out at least some basic expectations of the representativeness of the new Body's membership. How is the Body to be monitored to ensure it properly reflects the population of Wales, including sufficient representation and engagement of children and young people?

Children and young people are in a particularly disempowered position when it comes to participation in citizen engagement exercises - both because of their varying ability to advocate for themselves, but also in terms of feeling reassured that their views will be taken seriously when contributing to the work of organisations like the Citizen Voice Body.

The new Citizen Voice Body is a real opportunity to ensure that children and young people's voice are heard, and that comprehensive mechanisms for advocacy are established across health and social care.

Article 12 of the UNCRC is children and young people's right to be heard and to have their views taken seriously. Commenting on article 12's relevance to children and young people's right to enjoy the highest attainable standard of health (article 24), the UN Committee on the Rights of the Child explain that article 12...

...includes [children and young people's] views on all aspects of health provisions, including, for example, what services are needed, how and where they are best provided, barriers to accessing or using services, the quality of the services and the attitudes of health professionals, how to strengthen children's capacities to take increasing levels of responsibility for their own health and development, and how to involve them more effectively in the provision of services, as peer educators. States are encouraged to conduct regular participatory consultations, which are adapted to the age and maturity of the child, and research with children, and to do this separately with their parents, in order to learn about their health challenges, developmental needs and expectations as a contribution to the design of effective interventions and health programmes.⁵

I believe it is important for the Government to be clear in its intentions that the Body will be truly representative of the population, and how it expects this to be achieved in line with the UNCRC General Comment above, even if the Body itself determines the practicalities of these arrangements. While it is

⁵https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f15&Lang=en

encouraging to see the Welsh Government's view that it is 'essential the body has a strategy to maximise its engagement with members of the public', as argued in my response to the white paper, citizen empowerment should include engaging on issues outside of the agenda set (such as setting agenda items themselves, for example).

Ensuring that there are mechanisms for accountability (which is one of the five principles of my framework for a children's rights approach for public services in Wales, *The Right Way*⁶) is extremely important when establishing the Citizen Voice Body. The Bill gives little indication of how citizens who engage with the work of the Citizen Voice Body will be able to see clearly that their engagement has been properly taken into account by the Body, and by the health and social care organisations subject to the work of the Body.

I am concerned at the provision under section 16 of the Bill to exclude children and young people who currently have access to a statutory advocate under the Social Services and Well-being (Wales) Act 2014 from support from the Citizen Voice body:

The Citizen Voice Body may not provide assistance under subsection (6) to an individual if the individual is eligible for assistance in relation to the complaint by virtue of arrangements made under section 178(1)(a) of the 2014 Act (duty of local authorities to arrange assistance for children in respect of representations falling within section 174 of the 2014 Act).

While I understand that the Welsh Government's position is to exclude this group in order not to duplicate existing provisions, I do question how this sits with the ambition of creating a seamless alignment between health and social services for those children and young people who are eligible for advocacy under the 2014 Act but whose need for advocacy and support for complaints extends beyond their social services provision.

It would be helpful to have further information in relation to the position of existing local or regional bodies designed to ensure citizen voice influences policy, and how these would align with the new body. The new Body could take advantage of existing bodies such as the citizens' voice bodies within the Regional Partnership Boards, for example. The new Body could also work with the youth boards and panels in local authorities and health boards. These bodies are a unique way to gain the representative voice of children and young people involved in the work of health and social care organisations.

⁶ <https://www.childcomwales.org.uk/wp-content/uploads/2017/04/The-Right-Way.pdf>

The success of youth boards and the recent establishment of the youth parliament demonstrates the hugely positive impact that these bodies can have when given the proper opportunity to do so. This approach would also mean that the advantages of a local approach previously taken by CHCs would be maintained under the new system. However, it is also important that the new Body takes steps to ensure it takes account of views from every part of Wales, and that views and engagement from certain parts of Wales which may have more developed citizen voice mechanisms do not dominate the work of the Body.

The new Body should have the power to collate the expertise of these existing citizen voice groups, if this is the intended model.

It would have been helpful for the Bill to give more direction in terms of whether it intends the new Citizen Voice Body to involve direct representation, or whether it will be a central body for pulling together views from all of the existing representative bodies across health and social care in Wales.

Children's Rights Impact Assessment

I was pleased to see that a Children's Rights Impact Assessment (CRIA) has been completed for this Bill. The CRIA was made available to my office on request.

I was pleased to see direct reference made to specific articles of the UNCRC in this CRIA, and some detailing of the potential positive impact on children and young people, for example:

This new approach will ensure a consistency and uniformity of support for children, meaning that the advice and assistance available to them will not depend on which health board, trust of local authority is providing them with services.

While we agree that this Bill would lead to an improved consistency of access to support compared to CHCs, as outlined earlier in this response, we remain concerned that a wider offer of advocacy does not form part of this approach. Such an offer would have a positive impact on Children's Rights which would include a large proportion of the population of children and young people in Wales.

While I welcome the CRIA being undertaken, I am concerned that the summary of the Integrated Impact Assessment published alongside the Bill states that:

A Children's Rights Impact Assessment has concluded the Bill will not have a direct role in promoting the rights of a child or young person and is not expected to have any significant negative impacts. The CRIA outlines areas where some consequential positive impacts may be realised, such as those which may result from the Citizen Voice Body providing complaints advice and assistance to those children and young people who do not currently have a statutory right to an advocate under the Social Services and Well-Being (Wales) Act 2014.

It is disappointing that, while the CRIA itself points to several potential positive impacts for children and young people, the only potential pro-Rights effect is described in the Integrated Impact Assessment as 'consequential'. This alarms me. As there are no details in the Bill on how a Citizen Voice Body would actually look in terms of representation, I am concerned that the IIA's description of any impact as consequential suggests that realising children's participation in the Citizen Voice Body may not have been considered fully. This concern is further compounded by the lack of clarity within the Bill itself over where elements will apply to children and young people as well as adults. As children and young people are a particularly vulnerable group, and given the history of inconsistency over who is responsible for assistance and advice on complaints (between the Community Health Council or Local Health Board), this Bill should do more to be explicit where and how children and young people will be supported, and where and how children and young people will be able to engage with the new Citizen Voice Body. A thorough impact assessment could have highlighted the issues I have outlined in this response.

Conclusion

I welcome this Bill's provisions to better align health and social care in terms of quality and candour, and the setting up of new citizen engagement opportunities through the Citizen Voice Body. I am pleased that the provision of support for complaints for children and young people should now be provided through this national Body.

As outlined above, I am concerned over the lack of instruction given to the new Body in terms of ensuring the representation, engagement and involvement in coproduction of children and young people. This Bill

also provided an opportunity to put in motion work towards a comprehensive, broad advocacy offer for children and young people, across health and social care. With the narrow focus on complaints, however, this opportunity has not been taken up.

Submitted by:

A handwritten signature in black ink, appearing to read 'Sally Holland', written in a cursive style.

Professor Sally Holland
Children's Commissioner for Wales