

25 September 2018



Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to C

A written submission to the National Assembly for Wales Health, Social Care and Sport Committee from Together for Short Lives

1. We are the UK's leading charity for the 49,000 babies, children and young people in the UK living with life-limiting conditions and life-threatening conditions, and their families. Together with our members, we speak out for children and young people who are expected to have short lives. We are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.
2. We are a membership organisation and represent professionals and organisations spanning the statutory, voluntary and private sector who provide palliative care to babies, children and young people. These include children's hospices in Wales.
3. There are an estimated 1,000 children in Wales with life-limiting or life-threatening conditions.
4. We believe that the Social Services and Wellbeing (Wales) Act 2014 has potential to make sure that children in Wales with life-limiting conditions receive the social care assessments, plans and services they need. However, our members have identified a number of challenges with the way in which the act is being implemented.

The way in which assessments are carried out

5. Since the introduction of the legislation, some members have reported that the children and families they work with have experienced increasing difficulty in accessing a social care assessment. This can mean that children and families do not receive the care and support they need - or receive it too late. This increases their risk of needing to access acute, unplanned and expensive NHS care.
6. We ask the committee to recommend that the Welsh Government does more to hold local authorities to account to make sure that assessments are carried out when families need them.

The way in which the NHS and local authorities work with voluntary sector children's palliative care services

7. Voluntary sector providers, including children's hospices, bring social value to communities. When local NHS organisations and local authorities remunerate these charities for the children's palliative care they provide, the funding is matched and exceeded by charitable donations which also contribute to running services. Local volunteers also help to provide children's palliative care which are part-funded from statutory sources, further adding value.

8. Despite this, our members feel that too many local health boards and local authorities are failing to recognise the role that the voluntary sector children's palliative care providers can play. Our voluntary sector members are not receiving equitable and sustainable funding from local health boards and local authorities for the palliative care they provide.
9. Our voluntary sector members also feel that they are reaching children and their families too late in the course of their illness, because assessments that would allow for these lifeline services to be accessed sooner are being carried out too late.
10. We believe that this is caused, in part, by local authorities and local health boards not being clear about their responsibilities to work together to plan, fund and deliver children's palliative care services. This is particularly in terms of short breaks for respite for children with life-limiting conditions and their families, which are both a health and social care service. We ask the committee to recommend that the Welsh Government produces statutory guidance to clarify these responsibilities, and to hold local authorities and local health boards to account to make sure that they work together to jointly plan and fund children's palliative care services.

Transition to adulthood

11. For young people with life-limiting conditions, making the transition from children's to adult palliative care services is often described as like falling off a cliff edge. Medical advances mean there is now a growing number of young adults in Wales aged between 18 and 40 with life-limiting conditions. However, the transition these young people have to undergo from the comprehensive care offered by children's palliative care to unfamiliar adults' services can be daunting and is often not joined up. There are also too few palliative care services which meet the needs and wishes of young people in ways which are appropriate to their age and developmental stage, particularly in terms of the way in which short breaks are provided.
12. Young people with life-limiting conditions have specific needs which differ from both younger children and older adults. However, there is a lack of age and developmentally-appropriate palliative care services which can meet this growing demand. Young people with life-limiting conditions must forge relationships with new agencies and professionals, and for many young people, this transition coincides with a rapid decline of their condition.
13. It's also hard for these young people to get the support they need beyond their health needs, to do all the other things that all teenagers want to do: going out, living independently, exploring their sexuality, having relationships or entering the world of work and further education. Young people face too many barriers and obstacles, making it impossible for them to get on with enjoying adulthood. They need help now; they don't have the luxury of time on their hands.
14. Together for Short Lives is concerned that there is currently no statutory duty on local health boards and local authorities to work together to assess the future care and support needs of young people who are likely to need health and/or social care as adults. While we acknowledge that the Social Services and Wellbeing (Wales) Act applies to both children and adults, we ask that the committee to recommend that more is done to make sure that assessments, plans and services join up when a young person undergoes the transition to adulthood. This could include a new statutory right to a transition plan for young people which sets out the education, health and care they will need during this period.

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