

Paul Burstow MP  
Minister of State for Care Services (Health)  
Department of Health  
Richmond House  
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13 July 2011

Dear Minister

I am writing to you from the Childhood Bereavement Network (CBN), as the Government considers its response to the Palliative Care Funding Review. We met early in 2009, when you invited me to speak at a meeting of the All-Party Parliamentary Group on Well-being in Schools on how teachers and others can support pupils dealing with the death of someone important in their lives.

CBN is part of the National Children's Bureau, and is the hub for those working with bereaved children and young people – we have over 250 member organisations and individuals across the UK. We welcomed the terms and interim report of the Palliative Care Funding Review, and have submitted substantial evidence to the Review team. The Review clearly has enormous potential to improve outcomes for patients and iron out the inequities we see in palliative care across the country. However, we have some concerns about its implications for bereavement care for children.

#### **State funding of childhood bereavement services**

The Review's final report states that it is important that universal access to bereavement services is available for all children and young people if they need them, but acknowledges our evidence that such services are only available in 65-70% of areas (sec 5.8). Even where these services exist, they would not have the capacity to meet the needs of *all* the children in their area: some that are long established and well known by local schools and the community estimate that they reach only 50% of their target population. Thus the likelihood of being proactively offered and accepting a service before or after the death of a parent or sibling is still relatively low.

The report recommends that bereavement support 'continues to be supported by both the state and society, outside the palliative care tariff'. While we welcome the Review's aspiration for universal bereavement care, we do not see how the Review will help this aspiration to be realised. We are concerned that without further action, the recommendations will allow inequalities in support for bereaved children and young people to persist, or to worsen. If bereavement support is not to be included within the tariff, we seek assurances that more sustainable state funding will be provided for universal childhood bereavement services from sources outside the palliative care tariff, such as funding attached to the wider End of Life Care strategy.

**Pre-bereavement assessment**

The report recommends that a pre-bereavement assessment is included in the palliative care tariff (sec 5.8). We would like to be involved in developing the framework for assessing the needs of children and young people facing bereavement. However, we are concerned about a system which can assess needs, but has no powers to ensure those needs are met.

**Commissioning integrated pathways**

The report recommends that 'commissioners...should work jointly with providers to plan and commission integrated care packages which cover services provided by the state, voluntary or private sector. However, the totality of these services will not automatically be funded by the state' (sec 5.1). We are not clear how a commissioner would be incentivised to commission services they would not be funding, and – even if they did - how this would actually make a difference to what was provided locally.

**A way forward**

The report recommends a significant piloting phase to test out and develop its recommendations. We are very keen to be involved in the pilots, supporting them to collect evidence on the needs of bereaved children within their area, and to address these needs in line with the service models we have developed as a sector and in partnership with any existing services.

We are currently working together to develop a tool (initial phase funded by the Department of Health) for childhood bereavement services to measure their outcomes as defined by children, parents, practitioners and funders. We recommend that this tool is adopted by the pilots to evidence the difference that bereavement services are making in children's lives.

We would welcome a meeting with you to discuss the pilots and other ways in which support for bereaved children and young people could be improved and extended.

Yours sincerely

Alison Penny  
Coordinator

cc

Professor Sir Mike Richards