

Potential merits of a registry of bereaved children

Briefing for Westminster Hall debate 2.30pm 28 March 2023

Christine Jardine MP (Edinburgh West) has a Westminster Hall debate on 28 March 2023 on the potential merits of a registry of bereaved children and young people. The debate will focus in particular on the need for better data on children and young people who are bereaved, as a pre-requisite for more extensive and accessible support.

This briefing provides more information for those wishing to participate in the debate. Please contact us at cbn@ncb.org.uk if you would like more information on this briefing or our work.

Background

Bereavement is a universal experience, yet we know that the circumstances of each death, and the support received by those left behind, makes everyone's experience different. This is especially so for children and young people.

Bereavement affects every aspect of children's lives. The Childhood Bereavement Network's *Grief Matters for Children* campaign summarises evidence which shows that bereaved children are at increased risk of depressive symptoms and anxiety, physical health symptoms, accidents and serious illnesses, risky health behaviours and early mortality. They have lower average GCSE scores and are less likely to be employed at age 30. They are over-represented in the criminal justice system¹.

To mitigate the impact of bereavement on children's lives, the recent report of the independent UK Commission on Bereavement set out a vision that all bereaved families can easily find and access the right emotional bereavement support for their circumstances².

The problem

- This vision cannot be realised without robust data. Astonishingly, nobody knows exactly how many bereaved children and young people there are in the UK right now.
- No official data are collected each year on the number of children bereaved of a parent, sibling or someone else important in their lives.
- National data are collected on many other aspects of children's lives, including the number who are affected each year by the divorce of their parents.
- Effectively, this means that bereaved children are invisible in policy terms.
- Without knowing **how many** children and young people are bereaved each year, it is difficult to make the case for why this huge life change matters so much.
- Without knowing **which** children and young people have been bereaved, and where they are, it is impossible to contact the family proactively to find out what support they need.

¹ <https://childhoodbereavementnetwork.org.uk/sites/default/files/uploads/files/grief-matters-for-children-2017.pdf>

² <https://bereavementcommission.org.uk/ukcb-findings/>

The solution

- Collecting robust data on children and young people who have been bereaved, perhaps at the point at which a death is registered, would give us the information we need to make the case for, and offer, support.
- Data at different levels would help us tackle the difficulties we have identified.

Making the case

- Collecting data nationally on the number of children and young people bereaved of someone important would help to demonstrate the scale of child bereavement across the country, show what proportion of children are affected, and make the case for a national response.
- Collecting data locally on the number of children and young people bereaved would enable areas to plan appropriately for the level of service needed to respond to their needs.
- Strengthen the case for funding and support in an area that often struggles to be heard and recognised as an adverse childhood experience.

Monitoring the reach of services

- Local data on the number of children and young people bereaved could be combined with activity data from local services to identify what proportion of children and young people are getting support.

Getting support to families who need it

- Collecting data would provide an opportunity to signpost families that need it to local and national sources of support, by giving them relevant leaflets and contact information.
- With permission, families' contact details could also be passed to their local service, for the service to make a proactive approach. This is sometimes known as 'Real Time Referral' and is currently best established in services for families bereaved by suicide.

Understanding more about the impact of bereavement in childhood

- Data on which children and young people have been bereaved could be linked to other datasets, such as those on use of health services, to understand more about the impact of bereavement on children's health and futures.

Validating the experiences of children and young people

- Prioritising this would acknowledge that the feelings and experiences of young grieving people matter too, and give them access to the tools they need to rebuild their lives.

Suggested question:

Given the current invisibility of bereaved children in official statistics, what plans does the Government have to identify these children as a first step to meeting their needs?

Additional benefits

Better data on the number of children and young people bereaved each year would strengthen the case for change in other areas which would benefit bereaved children and young people. These are summarised below, with suggested points for the debate.

Grief education

- The UK Commission on Bereavement (2022) identified persistent discomfort in society about talking about dying and bereavement, which means bereaved children can miss out on the support they need from friends, family, and their communities.
- The Covid-19 pandemic confronted this generation of children with death and bereavement in an unprecedented way, both through direct experiences of bereavement, and through widespread discussion of these topics in the media.
- Learning about coping with bereavement as a part of life at school can help prepare pupils for their own experiences, and help them to support one another better. *'We should talk about it as it is a reality in life and a skill we need to learn for life. This would help us learn how to support others to cope.'* (Primary school pupil consulted via Votes for Schools)
- An increasing range of curriculum materials and training resources exist to help teachers' confidence in teaching these topics sensitively, helping prepare children to support one another and themselves at times of loss in the future, but they are not included in the statutory curriculum (for example in health education or relationships education), so many schools choose not to address them.
- The Commission recommended that 'all schools and other educational settings must be required to provide age-appropriate opportunities for children and young people to learn about coping with death and bereavement as part of life.'

Suggested question

What plans does the Government have to ensure that all children and young people are given opportunities to learn about coping with bereavement as part of life, to help them support themselves and their friends at times of loss?

Bereavement support at school

- Bereaved children and young people spend a significant proportion of their time in school or college, and should feel they 'belong'. As well as providing important social networks and stability, schools are places where children and young people have to study and perform, and so schools have a key role to play in providing the network of support around grieving pupils.
- The death of someone close can have a profoundly disruptive impact on children and young people's engagement and achievement at school.
- The UK Commission on Bereavement set out a principle that all bereaved children should be sensitively supported by their school or college during their bereavement.

- Where support from school was offered, all examples shared with the Commission highlighted a flexible approach to the child or young person: careful sharing of information, adjustments to expectations where needed, and flexible support that continued over time.
- However, half of the bereaved children, young people and adults who shared their experiences with the Commission said they got only a little or no support from their education setting after their bereavement.
- The Commission recommended that all schools should be required to have a bereavement policy including staff training, and a process for supporting bereaved children and their families.

Suggested question

Given the critical role that schools play in children's lives, what is the Government doing to improve the consistency of bereavement support in educational establishments, for pupils' wellbeing and learning?

Childhood bereavement and poverty

- Bereavement can often trigger financial insecurity and poverty, with many bereaved families at particular risk of financial hardship and changes to their living conditions.
- Among people nearing the end of life, people in families with children are the most vulnerable of all family types to experiencing poverty in the last five years of life. Two out of three working age terminally ill people with children will experience poverty in their last five years of life³.
- Bereavement benefits for families with children were radically reformed in 2017. 75% of families are worse off than they would have been under the old arrangements and, with the new payments made for only 18 months, 91% of families are supported for a shorter period⁴.
- These benefits have not been uprated at all since they were introduced in 2017, so they are now worth almost a fifth less than when they were introduced.
- Children and young people sharing their experiences with the Commission were very aware of the financial impact on their family and the stresses this was bringing *"I wish we had somewhere nicer to live and no money problems as this just makes things even harder for us."* (5-12 year old).
- These difficulties are worsening under the current cost of living crisis.

³ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-5th-pp.pdf>

⁴ <https://childhoodbereavementnetwork.org.uk/sites/default/files/uploads/files/BSP%20briefing%20March%202017.pdf>

Suggested questions

Will the Government uprate Bereavement Support Payment to address the almost 20% depreciation in its value since it was introduced in 2017, so that children and young people bereaved in 2023 and beyond are supported to the same degree as those bereaved five years ago?

Will the Government pay Bereavement Support Payment over a longer period, so that families have the breathing space they need to get back on their feet?

Will the Government relax proposed changes to work-search requirements under Universal Credit that will affect widowed parents of the youngest grieving children, forcing them to take up work or increase their hours when their children need them most?

Access to formal bereavement support

- Many children and young people will cope with the support of their family, friends, school and communities. But some, particularly those in circumstances that are already disadvantaged, will need more than this, and may benefit from meeting other bereaved children and young people or accessing therapeutic support such as counselling.
- Flexible, non-stigmatising community-based organisations typically provide a range of services including one to one and peer support groups for children and their parents or carers, along with support and training for schools and other professionals⁵.
- Where this sort of support was available, bereaved children and their parents shared with the Commission how helpful it was. They valued feeling understood, being able to talk, getting help managing their thoughts and feelings and remembering the person who had died, and building their confidence. Many bereaved children and young people liked meeting other children and young people in similar situations.
- However, many had struggled to get the support they needed.
- There is huge variation in the provision of these services across the UK. They have developed in an ad hoc way, leading to inequities in provision. Many struggle for funding, and large areas of the country are still without services that support all children, whatever the cause of death. Even in areas that do have a service, there may be long waiting lists or travel times, and services' survival is precarious.
- This results in many families struggling to find the help they need for their children. Prior to the pandemic, waiting lists for child bereavement services were increasing and there were already concerns about access.

⁵ <https://childhoodbereavementnetwork.org.uk/if-you-need-help-around-death/finding-support-local-you>

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- The pandemic exacerbated existing inequalities. Services are now faced with greater numbers of bereaved children and young people, grieving deaths in more difficult circumstances. Lockdowns made community fundraising more difficult and many services report reduced and precarious income.
- Even where services are available, families may struggle to find their way to them, or they may be provided in ways that do not match children's needs, with some groups being particularly underserved.
- The Commission called for the Government to invest 79p annually per child, young person and adult in the population to transform access to bereavement services over the next five years, including a particular focus on better supporting Black, Asian and ethnic minority communities.
- The Commission also called for bereavement services and support to sign up to an agreed set of standards, ensuring they meet the diverse needs of the communities they serve.

Suggested question

How does the Government plan to invest in equitable early support services for bereaved children and young people, helping to prevent difficulties worsening and becoming entrenched?