Submission to the Oireachtas Committee on Health and Children – Public hearing on End-of-Life Care
Executive Summary

This submission to the Joint Committee on Health and Children is made by the Irish Childhood Bereavement Network and refers to the nature and consequences of a child’s grief. It outlines the nature a significant bereavement can have on a child and highlights the uniqueness of children’s grief.

As children grow and develop in the context of the family, the report looks at the family dynamic in relation to grief and how this can impact on the grieving child.

It also describes what bereaved children need to overcome their sadness and loss and grow towards healing. It outlines the services which are available in Ireland to bereaved children and identifies the service gaps that need to be filled.

The report finishes with 4 key recommendations:

1. An agreed framework for community, public, volunteer and professional education with respect to childhood bereavement
2. An agreed research agenda with respect to childhood bereavement – consequences, impact and support
3. Continued support for networking of Irish and European bodies working in child bereavement
4. The development of existing and new services within an agreed framework that includes the development of Standards for Bereavement Care for children in Ireland
1.1 Introduction

The Irish Childhood Bereavement Network (ICBN) welcomes the opportunity to address the house. The vision of the ICBN is that by sharing and developing good practice, including training and resources, the care of children and their parents will be improved across Ireland. The ICBN works to a principle of equity – that each child should have the same opportunity for support regardless of where they live.

The Network is a national organization and represents the views of professionals working with bereaved children across Ireland. It was set-up in 2013 with funding from the Family Support Agency and the Irish Hospice Foundation. The Advisory Panel of the ICBN comprises of representatives of various agencies supporting bereaved children in Ireland, namely Our Lady’s Hospice, Dublin; Milford Care Centre, Limerick; Barnardos; the Family Support Agency; Beaumont Hospital, Dublin; Cois Cheim, Cork; Rainbows; Anam Cara; Association of Agency based Counselling in Ireland and the Irish Hospice Foundation.

The ICBN is a hub for those working with bereaved children, young people and their families in Ireland. It was established to:

Support professionals to deliver high quality and accessible bereavement support;

Signpost families and carers to a directory of bereavement support services;

Inform the general public regarding issues involved in childhood loss;

Advocate for bereaved children, young people and those supporting them.

Bereavement experiences amongst children are extremely common. There are no definite figures in Ireland as to how many children are bereaved of a significant person in their life but new research by the ESRI (Growing up in Ireland) demonstrates that 2.2% of nine year olds have lost a parent, 1.1% a sibling, 7% an aunt or uncle and 6% a close friend. By the age of nine 28% of Irish children have lost a grandparent.

Based on the 2011 census the Central Statistics Office provided us with information on the number of parents categorised as ‘Widow’ or ‘Widower’. Using these figures we know that 20,889 children and young people under 19 are currently bereaved of a mother or father. (It should be noted that these figures do not account for bereaved children whose parents were not married).

In the UK, estimates indicate 7% of children & young people will be bereaved of a parent by age 18.

1.2 Impact of bereavement on children

Reactions and outcomes to bereavement in childhood differ depending:

- The child’s age and personality,
- The child’s relationship with the deceased,
- The circumstances surrounding the death,
- The child’s social supports,
- The impact the death has on other members of the family/ how the family cope after the death
The changes the death brings for the child and previous losses experienced.

These factors can mediate or exacerbate the outcome for the child and the death of a person, coupled with the changes it brings to the child’s world that can result in behavioural and/or emotional stress reactions (Worden, 1996).

Some significant effects of childhood bereavement include:

- depression (in the short term or in adulthood),
- criminal or disruptive behaviours,
- early sexual activity,
- reduced educational attainment and employment status,
- leaving home early and
- diminished self-concept and self-esteem

However, not all the changes that bereavement brings are negative; some parentally bereaved young people report growth in areas such as having a more positive outlook, gratitude, appreciation of life, living life to the full and altruism (Brewer and Sparkes 2011).

1.3 The nature of children’s grief

Children who experience the death of a parent (or sibling) are likely to experience a time of disruption in the family which can be both confusing and worrying (Christ 2000; Silverman 2000). Most children oscillate naturally in their grieving as they grieve intermittently, often staying busy with the day-to-day living and facing their grief when a trigger causes them to engage with the loss (e.g. hearing a song or playing a sport that triggers memories of the deceased).

Rando (1991) explains that a child may manifest grief on an intermittent basis for many years in an ‘approach–avoidance’ cycle in order to manage their painful feelings.

‘the grief of children is like splashing in puddles while adult grief is like wading through a river’. Crossley (2000)

Children’s grief must be considered in terms of their developmental age and understanding of death as a concept. For example, a 2 year old does not understand that death is forever while a teenager understands that concept and may have unspoken worries about their own mortality.

A loss during formative years may have a long-term effect. Christ (2000) describes three models which might be useful in terms of representing the impact of grief on children; each of these is discussed briefly below.

The ‘Blunt Trauma’ model reflects the traditional view of childhood bereavement, whereby parental death is seen as a single event, a discrete blow that is ‘bounded in time, powerful in impact, and more disruptive for children than adolescents.’ This model focuses on the nature of the event and the developmental stage of the child when the death occurs.

The second model, the ‘Shock- Aftershock Wave’ model, emphasises the role of the death and subsequent multiple intervening factors which can continue to impact on a child’s development. A parent’s death is not seen as a single event that determines later outcome.
It is notable that changes take place within a child as he or she experiences and re-experiences grief during successive stages of development. Thus, refer to this process as a series of shocks and aftershocks.

The last model, called the ‘Cascade of Events’ is based on an expanded view of the long-term developmental effects of a parent’s death and how these manifest in the child. The term ‘cascade’ is designed to help clinicians understand:

- the interactions of the child’s developmental stage,
- the meaning of the parent’s/siblings death for the child,
- subsequent life stressors,
- the child’s vulnerability and resilience.

Depending on the support received these can lead to either a successful or detrimental adaptation to the loss. Thus, the death may trigger a cascade of significant life changes that will influence the child’s future development in the immediate and long term.

These models of adaptation have far-reaching implications for the services offered to bereaved children because the support required by children may need to extend over a period of time into adult life. The Candle Project in London refers to this as an ‘extended warranty’ (Kraus and Monroe, 2007). It is also worth noting finding that some negative outcomes do not appear in children until two years after their parent’s death, but we do not know whether, and for how long, these outcomes persist.

1.4 Children in the context of family

Children do not exist alone but are in a constant dynamic relationship within their family system. Death can become a major taboo subject in families when they are protecting themselves. This, in turn, can cause difficulties in talking to children about death in the family due to a script of silence that can prevail. However, it has been established that children need a caring adult to make sense of their losses for them in order to mourn (Black, 2002).

The role of the family is key in providing support to bereaved children. Openly expressing thoughts and feelings, tolerating different grieving styles, remaining flexible, and caring and supporting one another, enable a family to live with the change that death inflicts on their lives (Biggs, 2002). Collectively, these findings underline the importance of including parents and caregivers in children’s bereavement support provision.

Nadeau (1993) states that children will actively make meaning out of their experiences within the family unit, but this will depend on:

- their age,
- developmental stage,
- life experience, whilst they will also be
- the influence of other family members and how they model grief.

Support to children can be facilitated in the home with family members, in schools and parishes or through a range of supports available through health and social care services, which may be delivered through the statutory or voluntary sectors. Indeed, the first point of bereavement support for children lies in the family context and evidence suggests that children’s outcomes correlate strongly with their surviving parent’s:
The family context offers the optimum opportunity to provide children with continued routine activities, witness normal grief behaviours and engage in opportunities to remember the deceased. However, while parents are grieving themselves, it can be a significant strain to continue routines and remain emotionally and practically available to their children (Aynsley-Green et al., 2012).

Beyond the family, in school and other community contexts, adults and peers may be unsure what to say or how to help the bereaved child and as a result, evidence suggests that many children report having no one to talk to (Ribbens-McCarthy and Jessop, 2005).

1.5 What do bereaved children need?

There is a general consensus that children need:

- information and education on what death means;
- encouragement to talk about how they feel;
- reassurance that they are not to blame for the death;
- an opportunity to understand and express their grief;
- meet others and share experiences, and above all,
- access to support to generate hope for the future (e.g. Worden, 1996, Herbert, 1996).

Children also need inclusion at the time of illness, in the rituals of grief and in the grieving process of the family. They need to be able to let their ‘ebb and flow’ and to have understanding from those who support them.

This support is provided in the main not by ‘grief specialists’ but by extended family, teachers, youth workers and other adults in the child’s network.

Further supports must be set in a framework of standards and ‘best practice’.

Given the considerable array of factors that determine the outcome of childhood bereavement, it is clear, and supported by evidence that a range of bereavement supports for children, at different levels, are required to meet the needs of children and their families in a range of proactive and reactive ways (Akerman & Statham, 2011). Such an approach has been advocated by the Childhood Bereavement Network (2007) in the UK as outlined below:

John’s story below illustrates a bereaved child having his needs met and the positive impact this has had on his grieving process:

John aged 12 years was a young man bereaved suddenly of his father who died at work from a heart attack. The family unit was devastated by the loss and John’s mother who was five months pregnant at the time was inconsolable. John’s grandmother told him he was the
man of the house now. So John decided not to let Mam know how he was feeling about his father’s death and took it upon himself to take care of his little brother Cathal. His teacher noticed John becoming very withdrawn in the class and suggested to his mother that he might attend a child bereavement service in his area. John got on very well with the therapist as they explored his father's death and its meaning for him through play and conversation. John explained that he was worried in case the family would lose all their money as there was TB in some of the farms in a neighbouring county and he was afraid their farm would be next. The therapist told John that this was a heavy burden for a young boy to carry. They drew a back pack on a little boys back and started to unpack all the things John carried in worries and needed to let go. John left the session relieved. That night was the first in 8 months that he spoke with his mother of his father’s death. Mam too received the support she required and the family unit became functional again. They learned in time to accommodate the loss of their father and husband and John will complete his Leaving Certificate and hopes to go to college in September to follow a career path of his choice.

Figure 1: Levels of Bereavement Support for Children. CBN (2007).

1.6 The landscape of bereavement support for children in Ireland

A recent survey of children’s bereavement support services, representing a broad range of voluntary and statutory organisations, indicated that children’s bereavement services are using a diverse range of printed materials, have varying access to training and supervision and do not work to a common set of standards (Carroll, 2010). In addition, the Petrus report (2008) documented the difficulty in identifying up-to-date lists of bereavement service providers, including those serving children, across the country and outlined training and
standards targets for bereavement support providers which have not, to date, been operationalised.

The launch by the Department of Health and Children of their National Policy on Palliative Care for Children with Life-Limiting Conditions in Ireland (2009) provides hope for future service provision in relation to bereavement care. One of its key recommendations is that:

‘Bereavement supports for children’s palliative care should be developed according to a bereavement care continuum. Support should be offered at a level appropriate to the service user.’ p.35

This policy describes three levels of support and recommends that specific goals and measurable objectives are developed and explicit actions implemented. Reference is also made to the need for appropriately trained professionals and a standard of training and practice required for service delivery. Importantly, this is the first document to recognise the bereavement support needs of children in an Irish context and augurs well for the development of future policy in the area of childhood bereavement within palliative care services, albeit not at a broad community-based level where more traumatic deaths occur and children are exposed to death through illnesses which are not supported through palliative care as the death was sudden and unexpected.

While many children living in Dublin have access to a range of services there are children living in rural Ireland who have no local professional service to avail of if needed. As part of the scoping study into the feasibility of a Childhood Bereavement Network for Ireland (McLoughlin, 2012), a number of stakeholders working in the voluntary, statutory and private bereavement services were consulted to ascertain the current situation for bereaved children in Ireland.

Stakeholders acknowledged that there were aspects of bereavement support for children in Ireland that were working well but also that significant gaps in service provision exist -

1. Lack of a health promoting approach to childhood bereavement in schools and communities to enable the population to recognise death as a part of life and that childhood reactions to death, as experienced by the majority of children are “normal” reactions to a difficult event

2. Need for modules to be developed as part of SPHE focusing on death education for children and in the teacher training curriculum to enable teachers to deal with issues around death effectively

3. The high cost of attending private services for families is a factor we must consider and the lack of low cost/free services for families on low incomes. Whilst hospice’s provide excellent services to children these are not accessible to all bereaved by illness in the community

4. Inequity and fragmentation of services nationally – particularly outside Dublin

5. Increase in demand for services alongside annual funding cuts leading to some scaling back in services provided e.g. Barnardos

6. Financial and staffing constraints to future children’s bereavement service development and expansion e.g. limited funding to ICBN

7. Lack of continuity and employer support for individuals completing educational programmes Lack of dedicated services/recognition for children experiencing
complicated grief / multiple losses or those requiring 1-1 intervention and those extensive waiting lists for those that exist

8. Limited response by NEPS to bereavement in school situation beyond Critical Incident management and could include post-bereavement support

9. Lack of long term follow up on children who may need their support further into the trajectory of grief

10. Lack of quality/minimum standards / guidelines / regulation for service providers and agreed outcome measures

11. Health and social care staff unable to determine the quality/repute of children’s bereavement services available

12. Lack of supervision structures for a small minority who are providing children’s bereavement support

1.7 How to improve services for bereaved children

The ICBN believes there should be a multifaceted approach to providing nationwide support to all bereaved children who need it. The list of gaps above are underpinned by the need to develop an integrated and population based approach to providing support for bereaved children. Such an approach should

- Acknowledge the crucial role of family
- Be age-sensitive, proactive and responsive.
- Be guided by the Childhood Bereavement Network model (see figure 1) with activities and investment at five levels.
- Be cross-sectoral and strategic in nature, noting the role of communities, voluntary organisations as well as the education and health sector.
- Be inclusive – for example adult hospitals are often the context for children’s bereavement (such as the death of a parent or grandparent) yet children are often excluded
- Demonstrate adequate standard of training for health professionals and volunteers involved in providing bereavement care for children
- Provide adequate funds to services enabling both paid staff and volunteers
1.8 Recommendations

The ICBN makes the following recommendations to improve services for bereaved children in Ireland and those working in them:

A) An agreed framework for community, public, volunteer and professional education with respect to childhood bereavement

B) An agreed research agenda with respect to childhood bereavement – consequences, impact and support

C) Continued support for networking of Irish and European bodies working in childhood bereavement

D) The development of existing and new services within an agreed framework that includes the development of Standards for Bereavement Care for children in Ireland

A) An agreed framework for community, public, volunteer and professional education with respect to childhood bereavement

Education efforts should span from public & community initiatives (developing community awareness of children's grief through media and community education) through to formal professional and volunteer curricula for developing competence to support bereaved children.

The view of the ICBN is that particular emphasis should be focussed on schools. Given that bereavement occurs in a family context, and that the family can be undermined just at the time when it needs to be most supportive to children, school takes on a significant role in providing a predictable, stable and understanding environment.

The ICBN has already begun progressing the development of bereavement education to teachers and during Summer 2013 held Department of Education and Skills’ approved teacher’s summer school in partnership with IHF and Rainbows Ireland. The teachers at the school highlighted a desire to develop a language/vocabulary around bereavement, have practical supports and ‘teachable moments’ and guidance on how to support the child returning to school after a death as key needs in terms of supporting a bereaved child.

The Department of Education should promote a whole school approach to support a bereaved child. This would include incorporating children's grief into professional training and providing accessible continuing professional development. The inclusion of Death Education on the School curriculum in subjects such as Social Personal Health Education should also be considered.

B) An agreed research agenda with respect to childhood bereavement – consequences, impact and support

ICBN would welcome a research agenda to focus our collective efforts on supporting childhood bereavement in Ireland. The shape and consequences of childhood bereavement...
should be described and understood through longitudinal research. Similarly the most effective interventions at community, voluntary and professional level should be evidence-based. Finally, research represents an opportunity to ensure that children’s own views and experiences shape on-going support, policy and decision-making.

C) The development of existing and new services within an agreed framework that includes the development of Standards for Bereavement Care for children in Ireland

Children and families should have access to the range of flexible services they require. The gaps identified by those working in bereavement care in Ireland remain outstanding. Continued funding, standards for training and standards for best practice in bereavement care should be a priority.

D) Continued support for networking

Given that children’s bereavement support in Ireland is provided by a combination of voluntary, statutory and private agencies at different levels of intervention, there is a value in supporting them in a collective sense. If integrated bereavement care is to become the norm, if shared standards of care, training and resource are to be supported we contend that a network approach is one that will develop capacity across the range of existing services. The allocation of funding to continue the work of the network will help to strengthen the capacity of the sector and to further the recommendations proposed in this submission.

1.9 Conclusion

We have discussed the impact of bereavement on children, the nature of their grief, children’s context in the family, what support they need and what is available in Ireland. Our submission has laid out clearly 4 recommendations to the committee that we hope will be considered for implementation.

We believe that a comprehensive approach to children’s grief should include a ‘three legged stool approach’ where the child is the centre and the three supporting ‘legs’ represent family, school and formal children’s bereavement support services.

Our aim is to empower the natural support networks of family and schools to provide the supports bereaved children require through information and education.

For children who require added support due to the fact that the family structure has been devastated by the loss services should be accessible to all.
1.10 References


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