



The Irish Childhood Bereavement Network

Supporting those working with grieving children and young people

Foreword

Both the Irish Hospice Foundation (IHF) and the Family Support Agency (FSA) were very pleased to jointly support the development of a scoping study which explored the need for, and potential operation of, an Irish Childhood Bereavement Network. The study mapped out the vision of the network which was generated by voluntary and statutory providers of children's bereavement care in Ireland.

We know from international experience that such networks can greatly enhance the delivery of bereavement supports to children. By taking time to explore how a network might work in an Irish context, we have developed our thinking on the best way to deliver one.

Joint approaches between agencies deliver better long-term planning, enhancing value for investment and maximising available resources.

The FSA supports the delivery of bereavement counselling throughout Ireland through a national scheme of grants to voluntary organisations providing marriage, relationship, child and bereavement counselling services. The focus of the scheme is on the development of support services in the community for families, to enhance stability in family life and to assist families and their members in dealing with difficult periods which they may experience.

The IHF is committed to supporting the needs of bereaved people, and in particular to developing greater supports for groups such as children, who may be especially vulnerable when impacted by grief and loss.

Both organisations share a vision of providing services that are equitable, accessible and available to all who need them.

The IHF has been asked to take a lead in establishing the Irish Childhood Bereavement Network and is delighted to do so. The first priority will be to continue the engagement with committed stakeholders and to secure funding to support the Network's activities.

Both the IHF and the Steering Committee are most grateful to the Family Support Agency for funding the scoping study and to Dr Kathy McLoughlin who undertook the study. We also thank the participants from across Ireland who gave time to contributing their views on children's bereavement care.

We look forward to working with our international partners, particularly the CBN in the UK, and with national partners, including the AACI and the many voluntary and statutory agencies that are providing services for bereaved children in Ireland. We have a blueprint and a vision for the network generated by these groups; the ultimate measure of its success will be an improved service for bereaved children in Ireland and all those who support them.

Sharon Foley, CEO
The Irish Hospice Foundation

Bill O'Dea, CEO
Family Support Agency

July 2012

Children and Bereavement

There is a general consensus in the literature that children need information and education on what death means. They need encouragement to talk about how they feel, reassurance that they are not to blame for the death, opportunities to understand and express their grief, and above all, access to support which will promote resilience and self-confidence and give them hope for the future.

Bereavement support for 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 mental health, coping style, levels of warmth and discipline, and communication. The family context offers the best environment to provide children with routine activities, to witness normal grief behaviours and engage in opportunities to remember the person who has died. However, while parents are grieving themselves, it can be a significant strain to continue routines and remain emotionally and practically available to their children. 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 & Jessop, 2005).

Given the considerable array of factors that determine the outcome of childhood bereavement, it is clear that a range of bereavement supports, at different levels, are required to meet the needs of children and their families (Akerman & Statham, 2011). Such an approach has been advocated by the Childhood Bereavement Network (CBN) in the UK, as outlined in Fig 1.

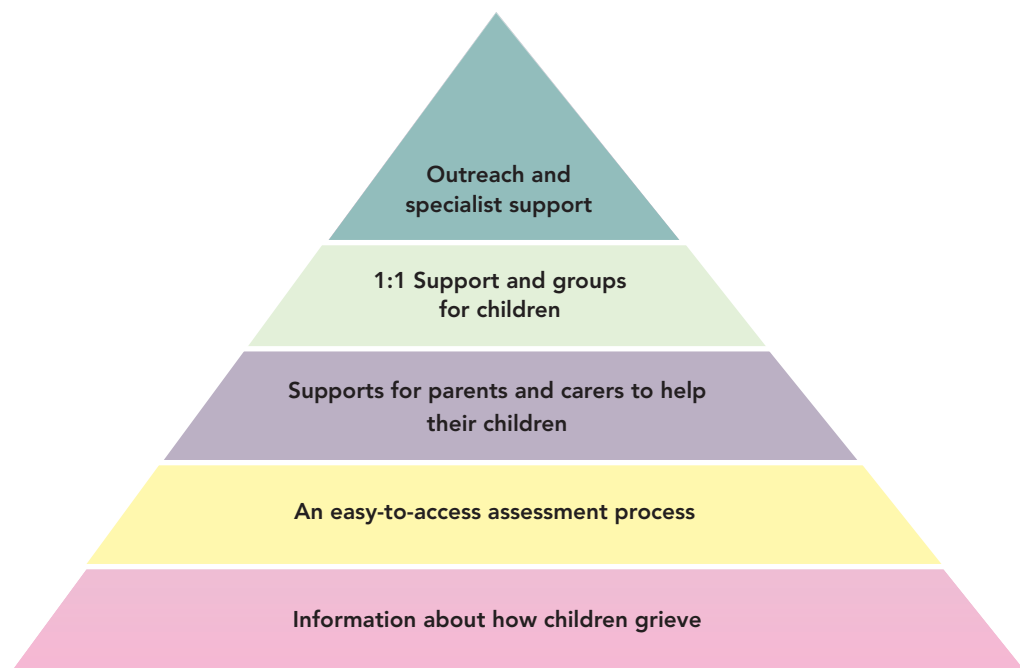


Figure 1: Levels of Bereavement Support for Children (CBN, 2007).

Children’s Bereavement Support in Ireland

Children’s bereavement support in Ireland is provided by a combination of voluntary, statutory and private agencies at different levels of intervention. Some service providers focus on children’s bereavement specifically, others provide it as one area of their work or more general psychosocial intervention. Children are also supported in their homes, schools and wider communities when a death occurs. Dowling et al. (2007) have highlighted that formalised support services in Ireland are limited for children, and a recent study by Brid Carroll *Survey of Childhood Bereavement Services in Ireland* (2010) outlines a need for services to demonstrate greater flexibility, for more inter-agency working and for greater awareness within communities about the impact bereavement can have on children and how they can be supported in the future.

A study by Keegan et al. (2000) highlighted a general consensus that the needs of bereaved individuals and their families are not being met. There is a lack of emphasis on childhood bereavement in government policy documents. For example, *Children First – National Guidance for the Protection & Welfare of Children* (updated 2011) gives no specific mention of bereavement service provision, and the *Report of the National Advisory Committee on Palliative Care* (2001) does not refer explicitly to children in the three levels of bereavement support identified. A review of general bereavement support services and specific services available following suicide bereavement was commissioned by the National Office for Suicide Prevention and conducted by Petrus Consulting et al (2008). This study provides a direction for bereavement service development in Ireland but did not include data or recommendations for children’s services.

The report echoed the view that bereavement support should be offered at different levels based on need, as outlined in Fig. 2.

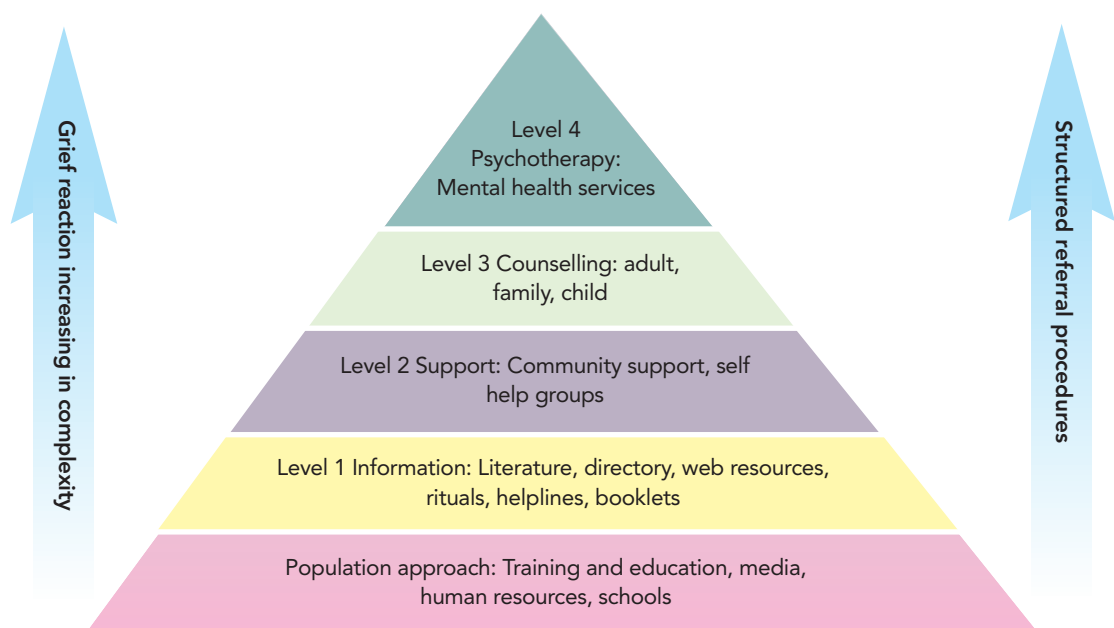


Figure 2: Levels of Bereavement Support (Petrus Consulting et al, 2008).

More recently, the inclusion of bereavement supports for children is noted in *Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy* (2009). This report recommends that bereavement supports for children be developed at appropriate levels and delivered by adequately trained staff to an agreed standard. This policy is relevant only to the siblings of children who die as a result of a life-limiting illness, and does not encompass those who experience the death of other relatives in a range of circumstances. Therefore there is a clear gap in government policy with regard to children's bereavement support provision across the population. This gap, together with (1) a nationally growing awareness of the rights of the child, with the appointment of both a Minister and an Ombudsman for Children; (2) increasing momentum regarding end-of-life service provision (e.g. the Irish Hospice Foundation's 'Hospice Friendly Hospitals' and 'Palliative Care for All' programmes; the HSE's clinical programme for palliative care; , and (3) increasing public dialogue regarding issues associated with death, dying, loss and care (e.g. the IHF's Forum on End of Life in Ireland and Milford Care Centre's 'Compassionate Communities') offers Ireland an opportunity to change the way it approaches childhood bereavement.

The recent *Survey of Childhood Bereavement Services in Ireland* (Carroll, 2010) indicated that children's bereavement services are utilising a diverse range of printed materials, have varying access to training and supervision and do not work to a common set of standards. In addition, the 2008 review of adult bereavement services (Petrus Consulting et al, 2008) documented difficulty in identifying up-to-date lists of bereavement service providers, including those serving children. The review also outlined training and standards targets for bereavement support providers which have not been put in place to date. In order to begin to address these needs, the Irish Hospice Foundation (IHF) held a Forum for children and young people's bereavement services at the end of May 2011, where the results of the Carroll survey were presented and facilitated group discussions were held. The Forum resulted in an agreement to develop a network for children's bereavement service providers and a request that the IHF progress this. A meeting of service providers who had expressed interest in the initiative was held in November 2011 and a steering committee was set up to progress the development of the network. The IHF then commissioned Dr Kathy McLoughlin to undertake a scoping study funded by the Family Support Agency. Contact with the UK Childhood Bereavement Network (CBN) was also established. The CBN has generously shared information about their network and has offered to work in partnership with Ireland to establish a sister network.

Summary of the scoping study: Establishing a Children's Bereavement Network in Ireland

(Dr Kathy McLoughlin)

The scoping study confirmed both an interest in and a perceived need for a network among practitioners working in childhood bereavement. Stakeholders acknowledged that some areas of service delivery were working well, with good community group programmes and independent practitioners available in some areas. The weaknesses highlighted by the stakeholders who attended focus groups included: a feeling of isolation in the work, the lack of a comprehensive directory of children's bereavement services, the lack of any forum for information exchange and knowledge dissemination and the impact of financial and staffing cuts. The study concluded that, subject to the allocation of baseline funding, such a network has the potential to positively impact on the weaknesses identified in bereavement services for children and young people in Ireland.

Key recommendations of the scoping study included;

- *That a network be established in Ireland to support those working in childhood bereavement.*
- *That the network adopts the following title and strap line:
"The Irish Childhood Bereavement Network"
*Supporting those working with grieving children and young people**
- *That the network build on the UK Childhood Bereavement Network model and explore opportunities to work collaboratively, formalising the relationship with the CBN to develop and share resources, opportunities and evidence, while maintaining independence.*
- *That the Steering Committee formally requests the Irish Childhood Bereavement Network be hosted by the Irish Hospice Foundation (IHF) for an initial period, subject to review.*
- *That the findings of this scoping study are utilised by the host organisation (IHF) to attract and secure funding for the next phase of the project.*
- *That the network be evaluated at the end of the five year term with an interim review after two years to determine the degree to which the network has achieved its objectives and impacted on children's bereavement services in Ireland.*

The steering committee has endorsed these recommendations and the Irish Hospice Foundation is pleased to host the network initially and to work towards securing funding to staff it. The scoping study has identified the need for an annual budget of €70,000 for the ICBN to meet its objectives. Securing this funding must now become a priority; however, any funds raised must be additional to existing funding for services. The IHF will shortly establish an advisory committee to enable us to progress this initiative.

Through collaboration with key national and international stakeholders, in particular the Childhood Bereavement Network in the UK and the Association for Agency-based Counselling in Ireland (AACI), there is an opportunity to add value to the work of bereavement services in Ireland and across the world. There is a clear willingness for children and young people's bereavement services to work together and opportunities exist to collaborate internationally with other relevant stakeholders. Such collaboration is fundamental in order to achieve this vision.

Thank you to the Steering Committee who oversaw the development and completion of this scoping study. The members were:

Ms Kate Burke, Anam Cara
Ms Brid Carroll, Family Life Services, Waterford
Ms Bernadette Connolly, St Luke's Hospital, Dublin
Ms Ann D'Arcy, Our Lady's Hospice and Care Services, Dublin
Ms Celine Deane, Beaumont Hospital, Dublin
Dr Susan Delaney, Irish Hospice Foundation, Dublin
Ms Lorraine Edwards, Waterford Regional Hospital
Ms Nuala Harmey, Children's University Hospital, Temple Street, Dublin
Mr John Hickey, Console, Dublin
Ms Anne-Marie Jones, Children's University Hospital, Temple Street, Dublin
Ms Orla Keegan, Irish Hospice Foundation, Dublin
Ms Pat McCarthy, Coisceim Counselling, Cork
Ms Estelle McGinley, Milford Care Centre, Limerick
Ms Fiona McInerney, Beaumont Hospital, Dublin
Ms Anne Staunton, Rainbows
Ms Marie Richardson, Milford Care Centre, Limerick

The Irish Childhood Bereavement Network (ICBN)

The ICBN will be a hub for those working with bereaved children, young people and their families in Ireland. We strengthen, support and provide added value to the work of our members, while respecting their diversity, to improve bereavement support for children and young people. Initially, the network will be hosted by the Irish Hospice Foundation and will be a virtual network. Subject to future dedicated resources, it is anticipated that the network will grow and enable the vision to be realised.

The vision

Collectively, we share and work towards a vision that all children and young people in Ireland, together with the adults in their lives, can easily access a choice of high-quality local and national information, guidance and support to enable them to manage the impact of death and loss on their lives. Members of the ICBN will collaborate to:

- Increase access to bereavement information, guidance and support services relevant to children and young people.
- Share their expertise, knowledge and experience to inform and support others.
- Improve the range and quality of bereavement support available to children, young people and those caring for them.

Centrally, the ICBN will act as a keystone for our members' partnership by:

- **Signposting** professionals and the public to sources of bereavement support, stating clearly what needs each service can address.
- **Supporting** professionals to find and share the knowledge and resources they need to deliver high-quality, effective, safe, evidence-based, accessible bereavement support.
- **Advocating** for bereaved children, young people and those supporting them, influencing policy, practice and public understanding.
- **Informing** the general public of the key issues involved in children and young people's loss and how they might support this population.
- **Generating** new ideas and approaches to improving bereavement support for children through education, research, policy and practice development.

As a network, we will:

- Respect the diversity of our members
- Be a listening and learning network
- Inform our work by the experience of children, young people, their families and those supporting them
- Ground our approaches in evidence from research
- Add value to our members' work
- Work collaboratively, both nationally and internationally.

Guiding principles

As members, we share the following eleven principles when working with bereaved children and young people:

- We acknowledge the child or young person's entitlement to grieve and to have their grief validated.
- We do not seek to protect children from loss and grief, but strive to facilitate their grief in a manner that promotes self-esteem and self-confidence, and develops communication, decision making and other life skills.
- We locate the child within their personal environment (family, religion, culture) and consider these factors before making any intervention.
- We ensure that appropriate family permission and involvement is seen as an integral part of the service we provide to children.
- We promote resilience in children.
- We acknowledge that grief is a normal response while also being aware of conditions or symptoms that may lead to difficulties in grief needing more formal intervention.
- Before intervening with a child we consider the advantages and disadvantages of utilising any intervention, drawing on evidence-based practice and/or standards where available.
- We work within our own competency and refer as appropriate.
- We are aware of issues pertaining to working with minors and adhere to safe, ethical and legal standards of practice and conduct.
- We have a clinical supervisor and colleagues with whom we can consult.
- We continue to update our skills, keeping abreast of new developments in the area of children and loss whilst monitoring our own service and outcomes.

Key References

Akerman, R. and Statham, J. (2011). *Childhood Bereavement: a Rapid Literature Review*. London: Child Wellbeing Research Centre. http://www.cwrc.ac.uk/resources/documents/Childhood_bereavement_literature_review_final_for_publication.pdf (accessed 14 March 2012).

Carroll, B. (2010). *Survey of Childhood Bereavement Services in Ireland*. MSc Bereavement Studies. IHF/RCSI. Ireland.

Childhood Bereavement Network: www.childhoodbereavementnetwork.org.uk

Department of Health and Children (2009). *Palliative Care for Children with Life Limiting Conditions in Ireland: A National Policy*. Dublin: Government Publications.

Department of Children and Youth Affairs (2011), *Children First: National Guidance for the Protection and Welfare of Children*, Government Publications

Dowling, M., Kiernan, G. and Guerin, S. (2007). Responding to the needs of children who have been bereaved: A focus on services in Ireland. *The Irish Psychologist*, 33 (10) 259-62.

IHF and HSE. (2008). *Palliative Care for All: Integrating Palliative Care into Disease Management Programmes*. Dublin: Irish Hospice Foundation.

Keegan, O., Kunin, H. and McGee, H. (2000). Bereavement Support in Ireland: A Quality Issue. *Journal of Health Gain*, 4:4 28-31.

McLoughlin, K. (2012) *Establishing a Children's Bereavement Support Network in Ireland. A Scoping Study*. Dublin: Irish Hospice Foundation

Department of Health (2001). *Report of the National Advisory Committee on Palliative Care*. Dublin; DOH&C.

Petrus Consulting, Bates, U., Jordan, N., Malone, K., Monahan, E., O'Connor, S., & Tiernan, E. (2008). *Review of general bereavement support and specific services available following suicide bereavement*. Dublin: NOSP.

Ribbens-McCarthy, J. and Jessop, J. (2005). *Young People, Bereavement and Loss: Disruptive transitions?* London: National Children's Bureau for the Joseph Rowntree Foundation.

Contributors

Thank you to all those who generously gave their time and expertise in the development of the vision for the Irish Childhood Bereavement Network:

Ursula Bates, Blackrock Hospice, Dublin
Marie Bowen, Jack and Jill Foundation
Deirdre Burke, Children's Guardian Project/Solicitor and Family Law Mediator
Pauline Carbery, Midland Regional Hospital, Portlaoise
Suzie Cahn, Art Therapist, Wicklow
Brid Carroll, Family Life Services, Waterford
Mary Casey, Sligo General Hospital, Sligo
Laura Coleman
Liz Coogan, Our Lady of Lourdes Hospital, Drogheda
Anne-Marie Curry, Palliative Care Services, Co Mayo
Bernadette Connolly, St Luke's Hospital, Dublin
Helen Culhane, Children's Grief Project, Limerick
Ann D'Arcy, Our Lady's Hospice and Care Services, Dublin
Celine Deane, Beaumont Hospital, Dublin
Deirdre Dowling, Irish Sudden Infant Death Association
Lorraine Edwards, Waterford Regional Hospital, Waterford
Nuala Harmeay, Children's University Hospital, Temple Street, Dublin
Anne-Marie Jones, Children's University Hospital, Temple Street, Dublin
Reamonn O'Donnchadha, Psychotherapist, Kerry
Orla Keegan, Irish Hospice Foundation
Catherine Keenan, St John of God Hospitaller Services
Valerie Kelly, Barnardos
Eilin Ni Mhurchu, Jack and Jill Foundation
Marie Richardson, Milford Care Centre, Limerick
Elaine Roub, Cruse, Northern Ireland
Rhona Kett-Sheridan, Jack and Jill Foundation
Siobhan Kiely, Milford Care Centre
Cathy Keighery, Jack and Jill Foundation
Pat McCarthy, The Social and Health Education Project, Cork
Margaret Naughton, Jack and Jill Foundation
Daniel Nuzum, Cork University Hospital
Ger O'Brien, Irish Sudden Infant Death Association
Alison Penny, Childhood Bereavement Network, UK.
Loretta Sheridan, Mayo General Hospital, Mayo
Denis Spillane, Mercy University Hospital, Cork
Therese Soden, Palliative Care Services, Mayo
Anne Staunton, Rainbows
Amanda Stavrou, Marymount Hospice, Cork
Anne Marie Tymlin, Dramatherapist, Dublin
Sharon Vard, Anamcara
Pauric Walsh, Ombudsman for Children's Office



The Irish Childhood Bereavement Network

Supporting those working with grieving children and young people

How do I join the ICBN?

The network is in the very early stages of development.
Currently you can register your interest by logging your details at:
<http://irishchildhoodbereavementnetwork.blogspot.ie>

You will be placed on a membership mailing list where you will receive information about the development of the network, news and events.

