The development of a framework to support bereaved children and young people: the Irish Childhood Bereavement Care Pyramid

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Title

The development of a framework to support strategic supports for bereaved children and young people: the Irish Childhood Bereavement Care Pyramid

Abstract

Children's bereavement poses a challenge not only for children themselves but for the families, communities, volunteers and professionals who support them. The Irish Childhood Bereavement Network set out to develop a framework to provide a comprehensive guide for children's bereavement support. The model is based on contemporary literature, existing policy and the views of professions, volunteers and parents. The process resulted in the 'Irish Childhood Bereavement Care Pyramid'. The major pillars of children's needs, support/service responses and staff competencies are described at four levels, basic up to complex.

The aim of the Pyramid is to guide adults to ensure that children are provided with the information and reassurance they need around a bereavement, to promote early intervention as appropriate and to recognise those few children who need specialist support to learn to live with their bereavement. Family context and the child's changing developmental status are emphasized as core considerations.

Keywords:

children; bereavement; policy; service; competence; need

INTRODUCTION TO ICBN

The Irish Childhood Bereavement Network (ICBN) is a hub for those working with bereaved children, young people and their families in Ireland. It was established in 2012 by a group of professionals and parents following an examination of the findings of a 2010 Irish audit of bereavement services for children (Carroll, 2010) which replicated the UK study by Rolls & Payne (2003).

In that study, a total of 122 services were identified and surveyed with valid responses received from 43 organisations. The situation in Ireland was similar to the UK in that there was a disparate range of one-to-one and group services, a feeling of isolation among practitioners, a lack of standardised training (embedded in original professional education or provided through unspecified continuous professional development offerings) and an ad-hoc approach to funding with more than half (53%) relying on grants and a further third relying on donations. Only three services dealt with childhood grief exclusively, others met bereavement issues as part of their general childhood support work or mental health service. While both state and voluntary organisations were approached in the research, in the main, childhood bereavement care was provided through the voluntary sector (60% of services including hospices, and community services).

Carroll (2010) also outlined the need for services to demonstrate greater flexibility and to develop more inter-agency working. In addition, there was a stated need for greater awareness within communities about the impact bereavement can have on children and how they can be supported.

Building on concerns raised in this research, a group of professionals and parent representatives working in the area of childhood bereavement came together to explore ways of making improvements. Consultation took place with Childhood Bereavement Network in the UK and the idea of a childhood bereavement network took hold. Following a feasibility study, the ICBN was set up with core funding from the statutory Child and Family Agency and from the Irish Hospice Foundation where the ICBN is housed.

The ICBN sets out 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; and

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

Children experience the death of a close family member daily. It is common. While there are no clear figures in Ireland about how many children experience significant bereavements in their lives, the “Growing up in Ireland” longitudinal research programme reports 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 (Williams & Morgan, 2012). Using the latest census figures, the Irish Central Statistics Office reports that in 2011 there were over 53,000 households with married single parents who were widowed with between one, two or three or more children living within that household (Central Statistics Office, 2012). In the UK, Ribbens McCarthy reports that up to 92% of young people “report having experienced bereavement with regard to what they consider to be a “close” or “significant” relationship before the age of 16” (Ribbens McCarthy, 2006, p. 16).

BACKGROUND: CHILDHOOD BEREAVEMENT

The current thinking in relation to the impact of bereavement on children is complex and, at times, contradictory (Ribbens McCarthy, 2006, Akerman & Straham, 2014). In a large study of bereaved children in the 1990's, Worden and his colleagues provided empirical evidence that children do indeed grieve and undertake grieving tasks similar to adults (Worden, 1996). He further concluded that children's grieving should be understood from the context of their cognitive, emotional, and social development. While this study was limited in relation to the cultural context of the children and type of bereavement they experienced, it did allow a moving away from previous more protectionist attitudes in relation to children and loss (Walker, 1993). However, it is now clear that while most children's reactions to a significant loss are “below the level that would indicate disorder”, a “substantial minority” experience “clinical levels of difficulty” (Akerman & Straham, 2014, p 6).

Children's reactions to bereavement

For those children who do experience a more pronounced reaction to their loss, research suggests a risk of emotional difficulties and behavioural problems (Gerhardt et al, 2012). Associated emotional reactions have been identified as: anxiety, depression, anger, guilt, loneliness, peer isolation, post-traumatic stress and suicidal ideation (Horsley & Patterson, 2006).

Walker (1993) found that behavioural and physical problems are also to be expected. Children can have a physical reaction to a loss that reflects the physical reactions experienced by adults (Walker, 1993; Stokes, 2004). Similarly, they may exhibit physical symptoms that are characteristic of a younger developmental age (eg. bed wetting, clinginess, thumb-sucking etc.). From a behavioural perspective, the child too can have sleep disturbance, loss of appetite, social withdrawal, lack of interest in usual activities, searching and calling out, over-activity (Stokes, 2004). All of the symptoms described above are usually temporary, resolving within days or weeks of the loss.

Children's understanding of death

There are essential cognitive developmental learning needs of the bereaved child or young person as outlined by Corr (1995):

1. *Universality* or the concept that all living thing will eventually die;
2. *Irreversibility* or the idea that once a living thing has died, it cannot become alive again;

3. *Non-functionality* or the concept that once a living body has died it cannot do any of the physical things it used to do;
4. *Causality* means that the child needs an accurate understanding of what can (and cannot) cause death;
5. *Some type of continuing life* or the idea of “soul” or an afterlife.

For younger children, the cognitive ability to understand all of these concepts does not exist, with all of these abilities not developing until approximately 12 years old (Saunders, 1996). Older children and adolescents understand these concepts more immediately in their grief journey but this can present additional challenges as they are met more immediately with the enormity of the loss (Horsley and Patterson, 2006).

Clear and unambiguous language and accurate factual information about the circumstances of the death is important for children in their understanding. Using words like “death” and “dies”, rather than “gone asleep”, helps the child to understand the different elements as described above (Mahon, 1994).

Family context

When a family member dies, a double loss can be experienced in that the child or young person loses not only a family member, but can also lose parental support (at least temporarily), as parent(s) are coping with their own grief (Morris, 2012). Children are often seen as the “forgotten” mourners in a family (Packman et al, 2006; Horsley & Patterson, 2006; Wender, 2012), as adults who surround them often do not understand the child’s need to grieve or are affected by their own loss in such a way as to be unable to recognise the child’s need to grieve also. For some families, bereavement comes on top of pre-existing stresses including poverty, financial struggles, mental health or addiction issues, that are already challenging for the family (Penny & Stubbs, 2014; Stephens et al, 2014; Harper et al, 2011; Stebbins et al, 2007).

As previously described, families are in a key position to address the needs of bereaved children, but parents can, at times, be so overwhelmed by their own grief that parenting and supporting their other children can feel like a struggle (Klass, 1996; de Cinque et al, 2006). In seeking their own support through their bereavement process, parents are actually strengthening their abilities to offer support to their children (Morris, 2012). However, in some circumstances, the situation surrounding the death of the child can result in the parents and families feeling alienated within their community (Saunders, 1995) and therefore finding it harder to look for support. Moreover, the general literature on parents’ help-seeking behaviours shows that a perception of stigma can account for large proportions of families avoiding help (Dempster et al, 2013).

The vast majority of children will develop the coping strategies to manage their grief with the support of their families and communities and go on to integrate the loss into their life experience (Stokes, 2009). In situations where the family members are struggling with their own grief, or face social complexities that do not allow them to be in a position to provide such support, outside interventions may be required (Wender, 2012). Finally, because of a

child's normal developmental patterns and needs, it should be recognised that a bereaved child's need for information and involvement can change over time as they understand the facts around a death differently as they grow (Creed, 2001).

In addition, attention should be paid to the complexities of the bereaved child's life, as well as the meaning that their family, community or culture attributes to the bereavement. These complexities "may be understood by reference to individual differences, family relationships, aspects of social structure and the clustering of certain experiences in processes over time" (Ribbens McCarthy, 2006, p. 125). In Ireland, for example, attention would need to be paid to the very specific beliefs and rituals around a death in the Traveller Community and for children within that community (McQuillan and Van Dorslaer, 2007)

GROUNDWORK FOR DEVELOPING A MODEL TO GUIDE RESPONSE TO CHILDHOOD BEREAVEMENT

The literature on childhood bereavement is complex, sometimes focusing only on one aspect of the child's loss, or at times providing contradictory messages, resulting in difficulties for practitioners in developing an understanding of the appropriate approach to bereaved children (Rolls & Payne, 2007; Penny & Stubbs, 2014). Out of the confusion evident in the literature, and acknowledging that many professionals and practitioners in Ireland only have intermittent contact with bereaved children, the ICBN agreed to develop a common explanatory framework as one of their priority pieces of work. The goal was to develop a reference point for adults who needed to informally or formally support bereaved children.

In developing the framework, a subgroup of the Steering Committee reviewed available frameworks, guidelines and recommendations for bereavement care and aligned models of childhood development (ICBN, 2014). Models which took a 'macro' perspective were deemed to be most relevant to provide a platform for planning and to be relevant to as broad an audience as possible.

Broad 'whole school' approaches to children's mental health and wellbeing were considered as were bereavement-specific and critical incident models. The Hardiker model for social policy and child development, a generic model used for planning purposes in the UK and Ireland, was identified as an important tool. It is based on the presumption that a broad focus on the universal/ basic level of support will prevent problems from arising for the majority of children. This is a population level model, often illustrated as a pyramid. It has four distinct levels moving from universal supports through to highly specialised and long-term services for children with very complex needs (Hardiker & Baker, 1995). Bereavement-specific frameworks reviewed included Worden's (1996) three levels of intervention, and Currier et al's (2007a & b) discussions of the public health model for bereavement care. This public health model also has three levels of bereavement care: that provided by family and

friends and natural supports open to all; bereavement care for those at risk of complications; and, finally, treatment provided by specialist mental health services.

Finally, adult models such as the three component model for bereavement in palliative and supportive care were also reviewed (NICE, 2004). There was evidently a commonality across these planning models – namely the intention to cater for the needs of ‘all’, ‘some’ and ‘few’ in terms of the complexity of their bereavement experiences.

However, no fully comprehensive framework for childhood bereavement existed, with each of the existing models focusing on a particular aspect (e.g. interventions) while excluding others (e.g. the skill requirements for practitioners, the role of the family). Consequently, a sub group of the ICBN was charged with developing a new and relevant model. The resulting work was piloted with individual parents of bereaved children, medical doctors, the hospital and hospice staff which provided confirmation of the clarity and usefulness of the model. No significant changes were made to the model as the feedback received from the reviewers was that the model allowed them to appropriately site the concerns they had about bereaved children and indicated to them what supports might be helpful within the context of that individual’s child’s life. It should be pointed out, however, that the model was designed to relate to the context of children living in Ireland for use within the community structure that exists here. Further feedback received during conferences and regional meetings of the ICBN has been very positive, with practitioners confirming the feedback received during the pilot phase.

BUILDING THE MODEL

The examination of frameworks described above allowed for three different facets of concern to adults when supporting a bereaved child or young person to be identified. These form the central elements of the Bereavement Care Pyramid, as follows:

- a) The **child’s needs**;
- b) The **supports and services** that are appropriate to address these needs;
- c) The **knowledge and competencies** required by those individuals who set out to provide information, support, counselling and psychotherapy to children and young people who experience bereavement .

Importantly bereaved children’s needs vary – there are universal needs for all bereaved children, with more specific needs evident for some children, while complex needs are experienced by fewer children.

Needs of bereaved children and young people

The first facet of concern is to identify the range of needs and varying responses of children who are bereaved (see Figure 1). Children and young people’s bereavement response have social, cognitive, emotional, physical and spiritual dimensions and all need to be contextualised within their particular material and cultural circumstances. A bereavement

or significant loss results in children and young people having to develop new and different coping strategies. As well as needing help and support around the time of bereavement, children may need to revisit their bereavement and “re-negotiate” their loss in the context of their changing cognitive abilities. Needs can be contextualised from basic to more complex.

Following his extensive study of bereaved children, Worden (1996) lists a number of key needs of a child at the time of death and during their bereavement journey. Such needs identified can be collectively summarised as falling into four overarching areas:

- the need for information;
- the opportunity to express feelings;
- reassurance; and
- involvement.

It is important that each child’s needs are considered within the context of their family, as well as recognising the child’s innate resilience to deal with such a loss (Stokes, 2004). Recognition too may be required for the different timeframe for such assessment in recognition of the pace of the child’s development (Kaplow et al, 2012). The child’s social and material circumstances also need to be taken into account, whether they presented challenges to the family before the bereavement or came to the fore as a result of the bereavement (Akerman & Statham, 2014).

Bereavement responses and needs should be contextualised in relation to the factors leading up to the death, the family circumstances and other day-to-day aspects of the child’s life. Studies show that while symptoms such as separation distress, depression, anxiety, behavioural issues and social withdrawal are, to some degree, aspects of the usual response to bereavement in childhood, these do not necessarily lead to psychological or pathological problems (Harrington & Harrison, 1999). However, there are particular circumstances where the usual resources of child/family are overwhelmed. In these situations, the child or family struggle to deal adequately with the demands created by the death and its aftermath. This may be particularly relevant in cases of suicide, traumatic or sudden deaths (Wender, 2012).

Figure 1 illustrates needs that apply to **most** children (Level 1), those that apply to **some** children (Level 2 and 3) and those that apply to **few** children (Level 4).

INSERT FIGURE ONE ABOUT HERE

Bereavement support and services for children and young people

This second facet explicitly sets out the various levels of support, types of care and interventions required in order to inform and signpost practitioners (see Figure 2). Support can range from information and guidance for all children through to psychotherapy and mental health interventions for a few children or young people who are experiencing serious emotional consequences of their bereavement (Penny & Stubbs, 2014).

The primary goals of basic support for children is to provide information, a clear explanation for their loss and to have key adults who are informed and emotionally available to them. This type of information is provided through families, schools, and community supports. The goals of organised and therapeutic services are to provide a “context of normalisation” to the range and intensity of a child’s experiences as part of their bereavement and to facilitate the child in developing coping strategies (Mahon, 1994).

Some benefits from these organised supports have been found for children who are not exhibiting pathological grief reactions (Akerman & Statham, 2014; Walijarvi et al, 2012). However, a review of community-based support services for bereaved children (Curtis & Newman, 2001) concluded that whilst benefits could result for many children, the case for including all bereaved children in such support programmes remains unproven. More recent reviews confirm this status (Currier et al 2007a, Rosner, 2010). Thus, individualised assessment of each child is crucial to establish the problems associated with the death, to review their individual strengths and resiliencies and to decide on the therapeutic support/interventions required to help them deal with such problems (Birenbaum, 2000). The efficacy of specialist psychotherapy and mental health services for those children with complex grief reactions has been demonstrated (Currier et al 2007, Rosner 2010).

The majority of children can be supported successfully within the family. While ‘generic’ responses and needs are detailed in Figure 2, the unique context of the particular child must be central when considering a response. Further, the ICBN believes that interventions at any level of the pyramid should:

- *Include the family*: recognising both the individual family’s needs for support but also recognising that the family is the main basis of support for the child (Gilliance *et al.*, 1997);
- *Allow the child and family a “settling down/readjustment” period before any specific therapeutic support is offered*: It can be difficult to know when is the “right” time to offer individual support to children and this can depend on many of the emotional and developmental factors discussed above (Gilliance et al, 1997);
- *Include work on “protective” factors, for example* by encouraging the development of the child’s understanding and new coping skills around grief so that they can learn to recognise and articulate the emotional impact of their loss in an age appropriate way (Akerman & Statham, 2014);
- *Be flexible enough to take into account each child’s needs, the circumstances of the child and their family including the level of family support that is available and the social environment that the child lives in including economic, environmental and cultural factors* (Akerman & Statham, 2014).

INSERT FIGURE TWO ABOUT HERE

Competencies for working with bereaved children/young people

The final aspect of the model examines the knowledge and experience required by individuals who work in this area in a professional or voluntary capacity (see Figure 3). Competencies support individuals and collective groups to examine how they perform, measure and develop their practice. However, there is no clear consensus in the literature as to what specifically constitutes a definition for competency (Becker 2007). The Council for Social Work Education in the US (2008) defines competency as ‘...measurable practice behaviours that are comprised of knowledge, values and skills’. To provide an acceptable standard of intervention to children and young people who are bereaved, as well as safe practice within the scope of knowledge, training and experience is essential.

In order to support the development of a professional approach, it is important that all those working in the area acquire the appropriate level of training to meet the needs of the children and young people they come in contact with, and to recognise the appropriateness of referring on when a more specialised service is required. No single competency tool exists for bereavement work with children. However, any framework should acknowledge the need for theoretical knowledge and experience to be developed in an incremental way.

The ICBN working group formulated the following working principles which it agreed should be adopted by all individuals, either professional or volunteer, when working with bereaved children:

- All practitioners providing support to children who experience a loss should have a basic understanding and knowledge of the potential impact of bereavement on children;
- Practitioners need an understanding of children and young people’s evolving needs and changing understanding of death as they progress through the developmental stages, paying due reference to their relevance to social and cultural context;
- Any support, counselling or therapeutic intervention with bereaved children should acknowledge the context of the child’s family/support system and should acknowledge and support the ability of that family/support system to care for and support the child in their bereavement taking into account their material circumstances and other family events that might impact on their child’s history and everyday life;
- Appropriate competencies to work with bereaved children and young people are developed through a combination of academic learning and practice wisdom gained working directly with bereaved children and young people within the context of regular supervision and mentoring;
- Everyone working in this area should work within their competencies.

Figure 3 below outlines the skills and competencies required to support children and young people experiencing bereavement at different levels of need, and through different levels of service type.

INSERT FIGURE 3 ABOUT HERE

THE MODEL – THE IRISH CHILDHOOD BEREAVEMENT CARE PYRAMID

Our aim was to develop a conceptual language to help those coming into contact with bereaved children to begin to craft appropriate responses. The major pillars of children's needs, support/service responses and staff competencies set out in Figures 1 to 3 were brought together into a comprehensive model for childhood bereavement care.

Consistent with established models, the Irish Childhood Bereavement Care Pyramid ("Pyramid") divides the different aspects of needs into four levels (ICBN, 2014). The Pyramid divides these needs into those that apply to most children (level 1), those that apply to some (level 2 and 3) and those that apply to few (level 4). The model then goes on to identify the supports and services required to support these needs and then identifies the competencies required to provide these services. Importantly, the Pyramid recognises the essential role of families and communities in supporting bereaved children and sees family members (in most situations) as the primary source of support for a child in this circumstance. It emphasises the impact of time on the bereavement processes for any child as well as the need to recognise the relevance of their developmental stage.

The call to family, practitioners and support organisations is to identify bereaved children's needs, and in turn to situate their own support, services and competence accordingly. Indeed the child or young person's view should be sought as well as the meaning that the child or young person places on the bereavement is central to its impact on them (Ribbens McCarthy, 2006). The model endorses assessment, acknowledges the resilience of children and makes a case for integrated service provision.

IIINSERT FIGURE FOUR ABOUT HERE

CONCLUSION

The literature on childhood bereavement can leave parents and professionals who have contact with children who have experienced a bereavement somewhat confused about how best to address those children's needs. In Ireland, this confusion is compounded by a lack of national approach or service for bereaved children. In order to address some of this confusion, the newly created ICBN sought to create a document that would provide a roadmap for those adults in helping them support bereaved children and, if required, refer them to the appropriate type of bereavement service.

In developing the Pyramid and its supporting document, the ICBN worked on the premise that individualised consideration of each child is crucial to establish the challenges associated with the death of their loved one and the responses and therapeutic support/interventions appropriate to help them deal with such problems (Birenbaum, 2000).

The Minister for Children launched the Irish Childhood Bereavement Care Pyramid in October 2014 following consultation with professionals and parent representatives who are regularly in contact with bereaved children. This work has been endorsed by TUSLA, the Child and Family Agency responsible for providing services to children and families nationally. The aim of the Pyramid is to guide adults to ensure that children and young people are provided with the information and reassurance they need around a bereavement, promote early intervention as appropriate to prevent further problems for children as they grow into adulthood, and to recognise those few children who need specialist support to learn to live with their bereavement. Further work is required to resource the adoption, promotion and the development of training based on the model.

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Figures

Figure One: Bereaved Children's Needs – from general (level 1) to complex (level 4)

Figure Two: Levels of bereavement support and service from general (Level 1) to professional mental health services (Level 4)

Figure Three: Levels of competences for those supporting and working with bereaved children from awareness (Level 1) up to expert knowledge and skill (Level 4)

Figure Four: Irish Childhood Bereavement Care Pyramid

Figure One: Bereaved Children's Needs – from general (level 1) to complex (level 4)

Level	Need
Level 1 – Need for Explanation and Reassurance	<p>Need support from family, extended family, from friends - much of children's understanding of the world comes through family & significant adults in their lives</p> <p>Need their families to have key information and resources in order to support with understanding</p> <p>Need age appropriate information in clear and concrete/concise language</p> <p>Need to have their thoughts, feelings and opinions listened to and acknowledged</p> <p>Need to know that it is okay not to be sad all of the time, children dip in and out of sadness</p> <p>Need to control some parts of their lives; have routines and predictability</p> <p>Need close relationships and reassurance</p>
Level 2 – Need to Normalise and Enhance Coping	<p>Need to feel less isolated and to meet others in similar situations</p> <p>Need to develop coping strategies and acknowledge feelings</p> <p>Need to build new explanations as they develop emotionally, cognitively & socially over time; revisiting what the loss means</p> <p>Need to have their thoughts, feelings and opinions listened to and acknowledged in a more formal setting and outside of the family</p> <p>Children need to develop a story of their changing life</p>
Level 3 – Additional Needs	<p>Help with grief reactions that are interfering with day to day engagement – marked changed behaviour /personality - anxiety, withdrawal, isolation, aggression, anger.</p> <p>Help with deaths which may be surrounded by secrecy or stigma</p> <p>Help to cope conflicting emotions, with guilt, confusion, blame and relief</p> <p>Extra help, for themselves & for families, to understand emotional and behavioural experiences of children with learning difficulties who are bereaved.</p>
Level 4 - Complex Needs	<p>Help with grief reactions and responses that are presenting as acute and require an immediate professional intervention –</p>

	<p>self harm, suicidal ideation, depression</p> <p>Help with pre-existing mental health issues such as anxiety/ depression</p> <p>Help with – persistent distress & preoccupation with circumstances of death</p>
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Figure Two: Levels of bereavement support and service from general (Level 1) to professional mental health services (Level 4)

Level	Services / Support
Level 1 – Information and Guidance	Accurate and honest age appropriate information Easily accessible via websites, leaflets, bereavement helplines Supportive family and community based responses
Level 2 – Organised Bereavement Support Services	Meeting others with similar experiences Help develop coping strategies Preferably community based activity Aim to decrease isolation, increase understanding Support services may explicitly involve parents/ family members to promote coping, and to provide opportunity for positive experience Often provided through voluntary sector
Level 3 – Professional Counselling	Appropriate child centred counselling Tailored for children with specific risk factors and/or who are experiencing difficulties relating to grief May be individual or group based approaches.
Level 4 - Psychotherapy and mental health service	Specialist service with core psychotherapeutic/ intervention protocol aiming to ameliorate complicated grief May include services which focus on symptoms of trauma May involve therapeutic work with family

Figure Three: Levels of competences for those supporting and working with bereaved children from awareness (Level 1) up to expert knowledge and skill (Level 4)

	COMPETENCIES
Level 1	Awareness that grief is a normal response to loss <ul style="list-style-type: none"> • Understanding of children's / young people's reaction to loss • Understanding levels of need • Awareness of how to access services
Level 2	Knowledge and basic skills <ul style="list-style-type: none"> • Knowledge of children / young people's response to loss • Knowledge of bereavement theory • Assessment, listening and empathy skills
Level 3	Advanced knowledge and skills <ul style="list-style-type: none"> • Academic qualification • Substantial clinical experience
Level 4	Expert knowledge and skills <ul style="list-style-type: none"> • Experience in childhood mental health

Figure Four: Irish Childhood Bereavement Care pyramid

The Irish Childhood Bereavement Care Pyramid

The Irish Childhood
Bereavement Network