

Standards for supporting Bereaved Children & Young People

A FRAMEWORK FOR DEVELOPMENT

DEVELOPED BY THE IRISH CHILDHOOD BEREAVEMENT NETWORK (ICBN)



DEVELOPED BY

**The Irish Childhood
Bereavement Network**

The Irish Childhood Bereavement Network (ICBN) was founded in 2012 to act as a hub for those working with bereaved children, young people and their families. Upon its establishment five key priority areas were outlined:

- 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;
- Generate new ideas and approaches to improving bereavement support for children.

The ICBN is a member organisation and membership is open to professionals working directly with bereaved children, those who occasionally support them and people interested in the area of children and young people's loss.

ICBN is proudly supported by Tulsa and the Irish Hospice Foundation.



Consultation process:

These are the first 'Standards' for supporting bereaved children and young people in Ireland. A draft version of the 'Standards' were circulated for a wide-ranging consultation process at the end of 2016. We received over 60 written feedback forms from organisations and individuals, all welcoming the work and providing vital insights and comments. We have made every effort to incorporate the views and comments into this final document.

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www.childhoodbereavement.ie

The ICBN website provides a wide range of information and resources to assist those supporting bereaved children and young people.

Glossary of Terms

Bereavement:

For the purposes of this document, bereavement refers to the loss through death of a person close to the child (for example a parent or a sibling).

Child/Children/Young People:

Defined for the purposes of this document as a child or young person up to their 18th birthday

Family:

The immediate adult and other children who normally live in a household with the child and provided daily care to them. Extended family refers to members of the child family network who may not live with the child, made up of grandparents, aunts, uncles, cousins and other significant individuals related by blood or by kinship.

Grief:

The processes that the child undergoes in order to understand and express the experience of their bereavement

ICBN:

Irish Childhood Bereavement Network

Pyramid:

Irish Childhood Bereavement Care Pyramid. People who are grieving may need different types of support. These can be explained using the pyramid of bereavement support which includes the various levels of support.

Foreward



On behalf of the Irish Childhood Bereavement Network (ICBN) I am delighted to present *'Standards for Supporting Bereaved Children & Young People – A Framework for Development' 2017*. The Standards have been developed as part of the ICBN's mission to highlight the needs of bereavement children and young people in Ireland. Since 2014, the ICBN has received core support from Tusla Child and Family Agency and from the Irish Hospice Foundation. Within the ICBN we work to promote the voice of bereaved children and young people in Ireland, acknowledging that theirs has traditionally been the silent voice of grieving.

In this document, we set out a way forward in the promotion of the child or young person's voice in Irish society, in order that their needs may be appropriately recognised and supported when they are bereaved. We use the language of standards to illustrate a multi-layered vision for bereavement support to emphasise the highest level of care that our bereaved children and young people deserve. In this way, the standards provide a framework to help us all improve and develop our care. We are not where we would like to be in providing that support and care yet, but it is important to set out standards to guide us in our journey and help us recognise when we have arrived.

The ICBN sees these standards being used for planning, provision, and quality review of childhood bereavement care. It is intended that these standards will be used in conjunction with other national and international standards that are relevant to this work. The ICBN intends this document to be used by all adults, professionals, volunteer organisations and policy makers who are concerned about bereaved children and young people.

We recognise that the coming years will be focused on the challenge of implementing these standards. We know that as individuals, families, communities and as a country we are at the beginning of a process. ICBN will review these standards and associated criteria every three years in the expectation that additional emphases, criteria and examples of achievement can be added.

The document has evolved from a wide consultation process and we thank all of those individuals, experts and organisations who have taken the time to provide feedback to us along the way. The Working Group has been kindly hosted by the IHF for its meetings and "think-ins". The ICBN Advisory Panel has been most helpful in their feedback and encouragement along the way, and thanks especially to Brid Carroll, for her sterling support and gentle steering when we hit some bumpy patches. Many thanks to Maura Keating, ICBN coordinator, who has brought these standards through their final consultation phase to this complete body of work and thanks also to her predecessor Nicola Jordan. But no project can come to fruition without the dedicated commitment of the core team of individuals who worked together to bring this project to fruition: Orla Keegan, Celine Deane, Estelle McGinley (with Pat McCarthy and Anne Staunton in earlier deliberations). Their willingness to be available at the crack of dawn to work on this project was mighty to behold!

Many and sincere thanks to you all.

Anne Marie Jones

Chair of ICBN Standards Sub Group and member of ICBN Advisory Panel

INTRODUCTION

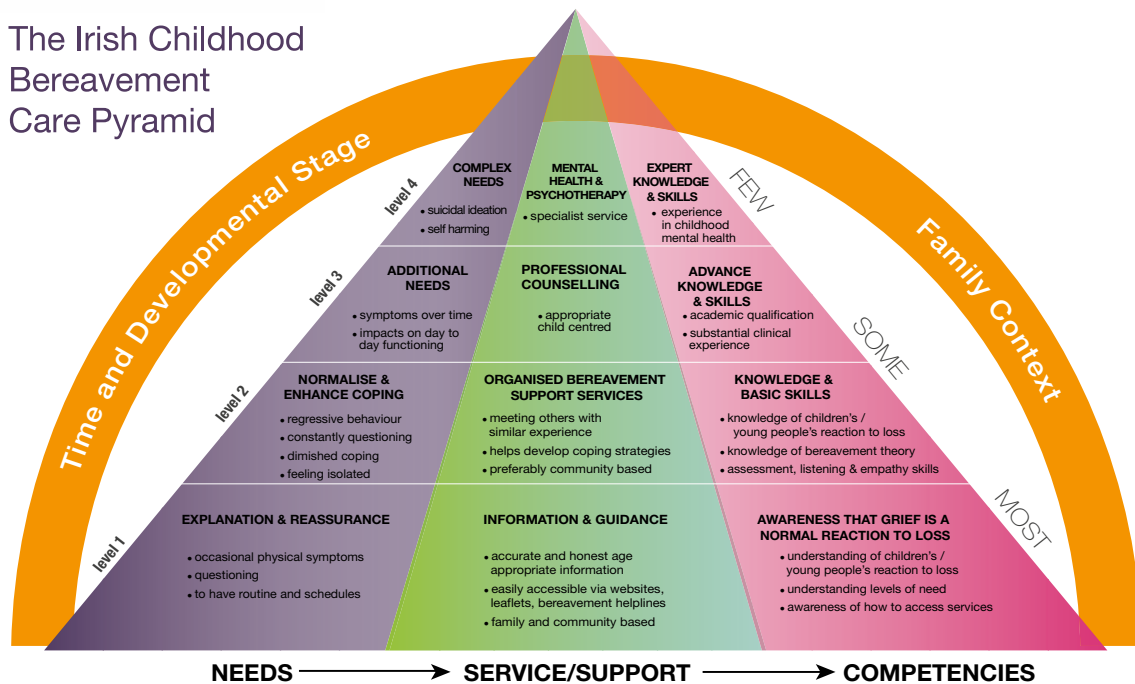
The Irish Childhood Bereavement Network (“ICBN”) works to promote the voice of bereaved children and young people, recognising that theirs has traditionally been the silent voice of grieving. The recognition that children’s grieving is similar to, but not the same as adults’, is not yet widely understood. In this document, the ICBN set out a way forward for the promotion of the child or young person’s voice in Irish society, in order that their needs may be appropriately recognised and supported when they are bereaved.

Understanding Childhood Bereavement (see Appendix A)

In discussing children’s bereavement it is essential to understand that:

- A large number of children experience bereavement in childhood; for example, two in every one hundred 9 year olds in Ireland have lost a parent. However, the loss of a parent is only one example of children’s loss which encompasses the death of any important person in their lives, be that a sibling, friend, grandparent, uncle or aunt or another person who is significant to them;
- Children’s understanding, reactions to and expression of grief depend on their cognitive, social and emotional development. Special attention needs to be paid to children who find situations with high emotion hard to manage, for example, children with special learning needs;
- The primary support for children and young people who are grieving is their family;
- Most children and young people manage their bereavement appropriately with the support of their family; some require interventions that normalise their grieving and promote the development of normal coping strategies;
- Grieving can become complicated for a minority of children and young people and individual professional support programmes will be required to help this small group of children come to terms with their bereavement;
- The context of a child’s and young person’s family history, their community and culture should be taken into account in their bereavement;
- At times, the nature of the death can also present particular challenges for a family. A sudden and unexpected death for example, often involves trauma for the children and young people concerned. Attention needs to be paid to the impact of such a sudden (often unexplainable) death for a child or young person as well as the family surrounding them;
- The bereavement needs of a child or young person should be taken into consideration as part of the preparation for an adult dying. This is particularly important in adult hospitals, where the majority of adult deaths in Ireland take place;
- Researchers who look at the long-term effects of bereavement on children and young people when they are adults are finding some long-term physical and mental health consequences well into later life for those bereaved of a parent or sibling in childhood. (see Appendix B)

The Irish Childhood Bereavement Care Pyramid



In 2015 the ICBN developed the Irish Childhood Bereavement Care Pyramid. The Pyramid identifies the needs of 'most', 'some' and 'few' bereaved children. It encourages adults who care for bereaved children to understand that, in most situations, children can be supported by providing accurate information and emotional support through their family and community. The Pyramid further identifies the types of services appropriate for 'some' and 'few' children who have extended needs and will require support outside of the home.

Developing Standards

In this next stage of our work, the ICBN has developed "Standards for Supporting Bereaved Children and Young People" contained in this document.

This work is undertaken with the expectation that the standards will have a number of functions:

1. To promote public and professional understanding of the impact of bereavement on children and the role of adults in bereaved children's lives;
2. To ensure that family and community are seen as having a key role in the support of bereaved children;
3. To act as an improvement framework for those working with bereaved children and their families;
4. To promote the concept that any services provided to bereaved children adhere to the highest standards when evaluated against the standards that have been set out;
5. To set out the role for policy makers locally and nationally to ensure that appropriate support is provided to children who are bereaved;
6. To act as a preventative mental health approach for bereaved children to reduce the likelihood of future mental health problems;
7. To underpin education and training at public, volunteer and professional levels.

We use the language of standards to illustrate a multi-layered vision for bereavement support to emphasise the highest level of care that our bereaved children deserve. In this way the standards provide a framework to help us all improve and develop our care.

The Standards

- Standard 1** **Child & Young Person:** *Children's experience of bereavement will be recognised, acknowledged and supported in accordance with their needs over time.*
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- Standard 2** **Family:** *The family is generally the main source of care for the bereaved child and will require access to reassurance, information, guidance and support to provide this care.*
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- Standard 3** **Local Community:** *All bereaved children should have access to bereavement information, guidance and support services in their local community as required.*
-
- Standard 4** **Service Providers:** *All service providers will ensure that governance, procedures and protocols are in place to ensure ethical, safe and appropriate bereavement service delivery to the children in their care.*
-
- Standard 5** **National:** *National policy and local infrastructure includes appropriate responses to, and integrates the needs of, bereaved children.*

In each section, a *rationale* for this standard is provided, with *criteria* for the demonstration of this standard presented. In addition, an explanation as to what this means for bereaved children is provided, as well as some examples of evidence of achievement. It is intended that these standards will be used in conjunction with other national and international standards that are relevant to this work. These standards and associated criteria will be reviewed by ICBN every three years in the expectation that additional emphases, criteria and examples of achievement can be added.

We accept that the coming years will be focused on the challenge of implementing these standards and consider that as individuals, families, communities and as a country we are at the beginning of a process.

Who are these Standards for

The ICBN intends this document to be used by all adults, professionals, volunteer organisations and policy makers who are concerned about bereaved children.

They are directed at adults who are caring for bereaved children and those who are in contact with bereaved children in their everyday lives such as teachers, childcare personnel, GPs, public health nurses, religious leaders. In addition they are relevant to groups of professionals who are in a position to provide targeted support to bereaved children, e.g. hospital staff, mental health professionals, social workers. Those whose core professional role is to provide support and counselling to bereaved children and families should also be expected to refer to the standards.

The standards are also designed to be used by community and national leaders who are concerned to include the needs of bereaved children in the development of local initiatives through political lobbying, funding initiatives and service developments. They are further intended to set out a national approach to the development of appropriate bereavement services for children and young people nationally.

The appropriate standard of care and support should be provided to children so that their bereavement needs can be met regardless of their religion, culture, gender or economic status or their location within Ireland.

How these standards can be used

These standards are designed to be clear, concise and comprehensive. The ICBN sees these standards being used for planning, provision, and quality review of childhood bereavement care.

1. *Planning – Standards may be used:*

- To promote a national “vision” for and shared understanding of children’s bereavement care in Ireland;
- To direct the ways in which communities, families, service providers and policy planners can promote resilience and provide support for bereaved children;
- To shape investment in bereavement care, to develop funding applications;
- To inform statutory commissioning of bereavement standards.

2. *Provision – Standards may be used:*

- To develop confidence in the information, supports and services available to bereaved children and their family and to promote informed choice and appropriate referrals;
- To ensure that bereavement support for children is based on the latest international findings in the field of children’s bereavement care;
- To help all of those involved in care for a bereaved child to define the scope of their care, responsibility and competence and to assist them identify complementary supports;
- To demonstrate strong & transparent governance through self-assessment;
- To ensure that the family are seen as central to the support provided to children and are supported appropriately;
- To ensure that service providers adhere to the best international standards in their work;
- To highlight the requirement for the voice of bereaved children to be integrated into national policies related to children.

3. *Quality review/ outcomes – Standards may be used:*

- To help service providers to review their current practices;
- To allow service providers incrementally develop their services in light of identified evolving needs of bereaved children.

The next section of this document sets out each of the five Standards in detail.

STANDARD 1

CHILD & YOUNG PERSON



Children's experience of bereavement will be recognised, acknowledged and supported in accordance with their needs over time.

Rationale

It is acknowledged that all children and young people have needs in the face of bereavement; needs that have similarities to but also differ from adults' grief. In addition, these needs will change through time. All adults in contact with a bereaved child may have a role in supporting them or responding to their needs – this may be support of an informal nature or more structured support.

Any information, assistance or service provided to children should take account of their age and developmental stage and also take cognisance of the circumstances of their bereavement and family functioning. The optimal timing for intervention cannot be standardised. Rather, the decision to intervene should be based on the child's individual needs and the extent of their resilience in managing the loss. Any interventions should have the appropriate consent of parents/guardians.

Children's reactions to bereavement

Following a death, children can experience various grief reactions – *Children may exhibit none, some or many of these responses*

- Emotional responses may include – fear, anxiety, confusion, anger, sadness, relief, loneliness, guilt, isolation;
- Physical responses may include – low energy, interrupted sleep/eating patterns, unexplained aches, pains;
- Behavioural responses may include – lack of concentration, memory loss, 'acting out', aggression, irritability or regression to behaviour more commonly associated with a younger age e.g. bed wetting, sucking thumb etc.;
- Social responses may include – loss of self-esteem and confidence, withdrawal from friends and activities – including school attendance.

It is essential to consider a child's understanding when a death has occurred. Clear and unambiguous language and accurate factual information about the circumstances of the death is important. More generally, children need help with normalising the experience; help with feelings or behaviours that are disrupting day-to-day life; or, for a very small number, help addressing suicidal thoughts/behaviour and other clinical issues. It should be noted that the timing of any formal interventions should be suited to and depend on the assessment of an individual child's needs.

All bereaved children and young people have the need for information, explanation and reassurance. In particular, older children and adolescents understand the finality of death straight away within their grief journey and this can present additional challenges as they come to terms with the enormity of the loss. Children with intellectual disabilities require special attention to make sure that the bereavement is clearly explained in a way that is appropriate for them and that their unique experiences are valued and supported.

Criteria to demonstrate the Standard has been met

1.1	Adults create opportunities to listen to and acknowledge the individual experience of grief for each child.
1.2	Children are given age appropriate information and guidance on what death means and how it might affect their lives.
1.3	Bereaved children have access to spontaneous opportunities for support through their family, carers, teachers and concerned adults.
1.4	Children have access to a level of support that meets their needs at a particular point in time during their bereavement process and additional services if required.
1.5	At different points of development children and young people have access to appropriate supports in accordance with their changing needs. Particular attention is required to ensure that appropriate supports during adolescence are available.

What does this mean for bereaved children?

- Children feel heard and understood and that their bereavement needs are being addressed.
- Bereaved children believe that their experience of bereavement is recognised and acknowledged by the important adults in their lives.
- Children are less likely to report feeling isolated.
- Children recognise that they have at least one key adult in their lives that they feel comfortable discussing their bereavement with.
- Children develop enhanced resilience and ability to cope with change as they mature.

Some practical examples of evidence of achievement

- Children and the adults in their lives have an awareness of the supports available.
- Childrens' bereavement needs are explicitly discussed and services explicitly assess their needs.
- Information and services are provided within a timeframe that meets the individual child's needs.

STANDARD 2

FAMILY



The family is generally the main source of care for the bereaved child and will require access to reassurance, information, guidance and support to provide this care.

Rationale

Any bereaved child should be seen in the context of their family. The family's strength and challenges are taken into account when assisting a family to ensure that the most appropriate type of support is accessed for their child.

It is well established that most children can manage and incorporate the grief they experience into their lives with the appropriate support from their family and key adults in their lives. However, this is based on the premise that the adults surrounding the child have accurate and up-to-date information on the impact of childhood bereavement. Additionally, families may not be in a position to provide this support if the bereavement has impacted them in a way that does not allow them to have sufficient resources to provide that support. In particular, when a death occurs that is sudden and unexpected, or is complicated by factors that are hard for the adults and children in this situation, extra support will be needed.

The Context of Family Support

Most children and young people will develop the coping strategies to manage their grief with the support of their families and communities. With this support, they will learn to integrate the loss into their life experience.

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.

Families are in a key position to address the needs of bereaved children. However, parents and carers can, at times, be so overwhelmed by their own grief that parenting and supporting children can feel like a struggle. In seeking their own support through their bereavement process, parents are actually strengthening their abilities to offer support to their children. However, in some circumstances, families can find it hard to integrate the support that is available due to their own grieving processes.

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.

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. As a result, children and young people can become the “forgotten” mourners in a family. 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. These pre-existing circumstances can place a large burden on families who are additionally dealing with the death of a loved one.

Criteria to demonstrate the Standard has been met

2.1	Families and caregivers have access to information, literature and guidance on what death means and the impact it may have on children, and the best ways of supporting children within their family.
2.2	Families have information and access to select external bereavement support services for their children.
2.3	Families play a key role in deciding the most appropriate support for them.
2.4	Counselling or other support provided directly to a child is designed to be complementary to any support provided to the child by the family.
2.5	Families are supported in a prompt and professional manner to ensure that their children’s bereavement needs are assessed and an appropriate programme of therapeutic support is provided.

What does this mean for bereaved children?

- Children will have their unique experience of grief recognised within the family context.
- Children are living in family units or other care arrangements where there is appropriate information about childhood bereavement and access to supports as needed.
- Children feel included in the family’s bereavement.
- The child experiences a secure and problem-solving environment for dealing with the bereavement with the support of outside services, if needed.
- The child knows that their family or carers will do their best to support them in their bereavement.
- If a family is not in a position to provide that level of support, then external support is secured.
- Agencies providing support to children who are bereaved should be mindful to ensure that their input does not undermine the natural support to be provided to families, rather that it supports and enhances same.

Some practical examples of evidence of achievement

- Children are included in rituals and events around the family's bereavement, such as funerals, anniversary rituals, events organised within the community to memorialise the deceased.
- Children are included in the discussion and decisions about appropriate source of bereavement support.
- Key adults recognise that children sometimes need support outside the home.
- Key adults have access to support and counselling that is specifically tailored to enable them to support the bereaved child(ren).
- There is information and support to address families experiencing sudden death.



STANDARD 3

LOCAL COMMUNITY

All bereaved children should have access to bereavement information, guidance and support services in their local community as required.

Rationale

Children benefit from support and understanding in their local community which includes cultural, ethnic, religious and geographical norms. Having access to adults who understand and acknowledge their grief helps to normalise their grieving process. The support provided to grieving children can come from adults in their lives, and from voluntary or statutory organisations in their community.

It is important to realise that a 'community' may be virtual and many children and young people access support and information through digital and social media channels.

To ensure quality services in all regions these services should be:

- provided in a prompt fashion;
- in keeping with the child's needs;
- in keeping with the family needs;
- age appropriate;
- as close to home as possible; and
- provided regardless of religion, culture, gender and economic status.

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. Family practices within their community in relation to the inclusion (or not) of children in bereavement rituals, the recognition (or not) of the impact of grieving on the child, or the long-term effects on the child's life can affect how a child develops appropriate coping strategies around their loss.

Criteria to demonstrate the Standard has been met

3.1	At a minimum, information about children's bereavement and support available locally will be available in doctors' surgeries, health centres, primary care centres, hospitals, hospital mortuaries, libraries, citizen advice bureaus, churches, schools, local children's organisations.
3.2	Local communities will be able to access national advice and information services/ phonelines at low cost.
3.3	Children will always be given the opportunity to be included in local bereavement events and rituals.
3.4	Specialist services for children experiencing complications (Level 4 on bereavement pyramid) are provided at a regional level but will be accessed through a local referral system, e.g. the child's G.P.
3.5	Adults who believe they require support because of their experience of bereavement in childhood will be able to access appropriate services and supports in their community.

What does this mean for bereaved children?

- Bereaved children believe adults they encounter in their day-to-day activities understand their bereavement.
- Children can get support in their local community, either informally or through services.
- Those children with complex bereavement needs are being treated for these needs in a prompt fashion by an appropriately qualified professional.

Some practical examples of evidence of achievement

- Information on childhood bereavement is provided through local community structures.
- The services of national organisations are accessible locally, including telephone and one-to-one support.



STANDARD 4

SERVICE PROVIDERS

All service providers will ensure that governance, procedures and protocols are in place to ensure ethical, safe and appropriate bereavement service delivery to the children in their care.

Rationale

There is now a greater understanding that some children will experience problems in coping with the death of a significant person in their life. A smaller proportion of bereaved children will be regarded as especially vulnerable and requiring clinical intervention to facilitate their adjustment to the loss. Adolescents in particular are more at risk of developing some degree of mental health problem following the death of a close family member.

Problems may include increases in anxiety, depression and substance misuse especially in the first year after a bereavement. Some of the personal changes reported by adolescents include personality, school work, goals/life perspective, activities and interests as well as changes in relationships with family and peers.

It is worth restating that the majority of children cope well with bereavement with family support, however professionals who work with children recognise the enduring impact that the loss of someone close can have on all facets of a child's life, their functioning and well-being.

Individuals or services providing formal support must operate according to standards of best practice as set out below. It is recommended that each provider would review their service, its governance and engage in continuous improvement.

Currently in Ireland bereavement services are provided through voluntary, religious and statutory organisations, as well as by individual practitioners. This makes for large variation in service delivery. This standard provides guidance to all stakeholders in support of appropriate governance and service provision.

In addition, individuals working in an organisation or alone, should be accredited by the relevant professional or national body. (See Appendix C)

Criteria to demonstrate the Standard has been met

- 4.1 Any organization providing bereavement services to children should ensure that their governance structure includes:
- 4.1.1 Clear, accurate and up to date written information outlining the range of services and identifies the level(s) of specific need it can meet.
 - 4.1.2 A clearly documented model of care.
 - 4.1.3 Knowledge of contemporary understanding of children's grief and appropriate interventions.
 - 4.1.4 Information on children's bereavement through leaflets, useful links, websites, information on further reading materials.
 - 4.1.5 Clearly identified referral pathways to all levels of bereavement support offered by a service provider.
 - 4.1.6 Written consent of parents or guardians for children to access services and verbal assent from the child who is availing of support.
 - 4.1.7 Transparent assessment of the child's bereavement intervention needs to ensure that the service being offered is the most appropriate at that time.
 - 4.1.8 An assessment procedure that ensures that the child's bereavement needs can be met by the service provider.
 - 4.1.9 A governance structure that clarifies ongoing referral pathway, if the organisation finds that the child's needs do not fit with the service being provided.
 - 4.1.10 Evaluation and feedback policies and procedures.
 - 4.1.11 Policies and procedures to ensure that records are maintained in a confidential manner in accordance with the Data Protection Act (1988), the Data Protection Amendment Act (2003) and the Freedom of Information Act 2014.
 - 4.1.12 Practitioners who are aware of the limitations of the confidentiality commitment when working with children.
 - 4.1.13 A safe process of recruitment, selection and probation for service personnel and volunteers.
 - 4.1.14 Adherence to the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016.
 - 4.1.15 Adherence to Children First Act 2015 and National Child Protection Guidelines.
 - 4.1.16 Training and support of all staff and volunteers to underpin the service level provided.
 - 4.1.17 Assurance that individuals involved in supporting bereaved children shall engage in regular professional supervision, Continuous Professional Development and self-care activities.
 - 4.1.18 Assurance that persons providing support shall do so in an ethical manner, in accordance with the Code of Ethics pertaining to their particular profession.
 - 4.1.19 Agencies shall seek and create opportunities to work collaboratively with other organisations providing support to children and families who experience bereavement.
 - 4.1.20 Organisations shall ensure that all necessary governance procedures are in place to guarantee a transparent service which is run to the highest standards (as set out in 'Your guide to the governance code for community, voluntary and charitable organisations', published by the Department of Education and Skills).
 - 4.1.21 Professionals should adhere to relevant national regulatory requirements.

What does this mean for bereaved children?

- Children and their family can be confident that the services provided are safe and adhering to best practice standards.
- Adults caring for children will be working within appropriate professional frameworks.

Some practical examples of evidence of achievement

- Organisations providing services to bereaved children adhere to the above standards and self-assess at least every two years.
- Providers have clear and appropriate governance structures.
- Service plans reflect organisational commitment to serving bereaved children.

STANDARD 5 NATIONAL



National policy and local infrastructure includes appropriate responses to, and integrates the needs of, bereaved children.

Rationale

Children are not immune from the impact of bereavement. Estimates range between 4% and 5% as to the proportion who will be bereaved of a parent by 18 years of age. In Ireland the 'Growing up in Ireland' study showed that 2.2% of 9 year olds had lost a parent, 1% a sibling and 28% had experienced the death of a grandparent.

While the actual loss or death of a person is an 'event', the consequences of the loss are carried from childhood to adulthood. International population studies have begun to show long-term mental health and physical health deficits for cohorts of bereaved children. While this line of research is relatively new, it makes the compelling case for research and a focus on bereavement in national children's policy development in Ireland.

With this increased understanding of the immediate, medium-term and long-term impacts of the loss of a family member, it is critical that the needs of bereaved children and young people in Ireland are identified and addressed as early as possible.

It is now evidenced internationally that acknowledging and providing appropriate support to bereaved children and their families has a positive effect on their wellbeing and health. This means that it is essential to adopt a public health approach to bereavement and its consequences.

Consequently, it is critical to:

- advocate for and develop a coherent national childhood bereavement policy;
- promote positive mental health and develop services nationally in order to minimize difficulties for bereaved children into the future;
- influence educational curricula for children, adults and professionals;
- engage in public education;
- ensure that bereaved children are nurtured and protected from a range of hardships that may result from their loss – e.g., economic or educational changes.

Criteria to demonstrate the Standard has been met

5.1	The impact of bereavement on children is integrated into a range of national policies.
5.2	A national approach or framework for the provision of support for bereaved children is developed and adopted to underpin decisions about resources and developments from statutory bodies.
5.3	National approaches are built upon a principle of collaboration, and local collaborative structures are resourced and promoted accordingly.
5.4	National education and training programmes for professionals include education on bereavement and childhood bereavement.
5.5	National research on childhood bereavement is promoted through an agreed research agenda – including population level research.
5.6	The economic and social consequences of bereavement are acknowledged and priority given to reducing their negative impact on a bereaved child and their family.
5.7	National approaches and strategies are informed by ongoing consultation with bereaved children and those who care for and support them.

What does this mean for bereaved children?

- Childhood Bereavement is normalized as part of life.
- Bereaved children's needs are legitimized and recognized by being reflected in national policy.
- National recognition of the changed circumstances for children and young people following loss.
- Appropriate resources are available to respond proactively and to meet this changed need.

Some practical examples of evidence of achievement

- Bereaved children will have equitable access to the supports required regardless of religion, economic status, gender, location, ethnicity.
- There is a public bereavement education campaign.
- The inclusion of bereavement education on professionals' curricula.
- Recommendations from policies are implemented and tracked.
- There is accurate data on the numbers and ages of bereaved children in Ireland.
- A National Childhood Bereavement Strategy is developed and implemented.

Appendix A

Children's Understanding of Death

Children's grief

How children understand and react to grief depends on their age and stage of development. They gradually understand more as they mature. It is important to realise what your child understands about death so that you can help them if they are confused about what is happening. The following guidelines are general and may help you:

Children's Understanding of Death

0-2 Years

After a death in the family it is common for a baby to become withdrawn or display outbursts of loud crying and angry tears. Although infants do not understand death, they know when things have changed and may react to a person's absence. This may show in clinginess and distress. Maintaining the child's routine and making them feel secure are the most important ways to support children of this age.

2-5 Years

Children still do not fully understand death at this age. They don't realise that death is permanent and is something that happens to everyone at some time. They need to know the person who died cannot return and that they are not simply asleep. They worry that something they said or did may have caused the death and need reassurance to know that it is not their fault. Children should be encouraged to ask questions which should be answered openly and simply. Children often ask the same questions over and over again. Answering these questions patiently will help them and give them reassurance.

5-8 Years

Children gradually learn that death is final and that all people will die at some time. This may make them worry that other people close to them will also die. It can help children to talk about these fears. We can't promise children that no-one will ever die in the family but we can help them to feel safe by telling them that they will always be looked after. It can help children if they are encouraged to talk about and express their feelings, no matter what the feelings are. More curious children in this age group often ask direct questions about what has happened the body as they are trying to understand. They may blame themselves in some way for the death and can engage in 'magical thinking', filling the gaps when information has not been given to them.

8-12 Years

They understand that death is irreversible, universal and has a cause. Grief can express itself through physical aches and pains and challenging behaviour. It is important not to place unnecessary responsibility on children of this age especially eldest children who may

feel responsible for younger siblings or boys who take on the role of the man of the house if their father has died. Reassurances about changes in lifestyle such as money and whether they can remain in the family home should be given.

Adolescence

Adolescence is a time of great change in the life of a young person. Teenagers struggle with issues of identity and independence, as they try to bridge the gap between childhood and adulthood. When a death occurs their life can become very difficult.

It is important to give adolescents clear and accurate information at the time of a death. They may wish to take an active part in the funeral arrangements or to mark the death in their own way. Involving teens in the rituals can help them with their grief journey as it can give them a sense of control at a difficult time. It is important to treat them in a manner appropriate to their age.

Unlike young children, adolescents fully understand the concept of death; they know that death is final and inevitable. However, confusion arises as they struggle with the multiples of emotions, thoughts and mood changes that the death creates while trying to remain similar to their peers.

Appendix B

Background to Childhood Bereavement

Childhood bereavement

Children's actual experience of grief and bereavement has only relatively recently become a focus of research. It has now become clear that the nature of children's grieving is qualitatively different to adults (Stokes, 2004).

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). 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). Higher grief intensity, longer duration or inhibited grief are features of 'complicated' grief in children but work remains to be done in assessing and identifying this experience in practice (Dyregov and Dyregov, 2013).

Prevalence

Children are not immune from the fact of bereavement and estimates range between 4% (Rostila, 2015) and 5% (United Kingdom) as to the proportion who will be bereaved of a parent by 18 years of age. In Ireland the 'Growing up in Ireland' study showed that 2.2% of 9 year olds had lost a parent, 1% a sibling and 28% had experienced the death of a grandparent (Williams & Morgan, 2012).

Children's reactions to bereavement

Following a death, children can experience various grief reactions –

- Emotional responses may include – fear, anxiety, confusion, anger, sadness, relief, loneliness, guilt, isolation;
- Physical responses may include – low energy, interrupted sleep/eating patterns, unexplained aches, pains;
- Behavioural responses may include – lack of concentration, memory loss, 'acting out', aggression, irritability or regression to behaviour more commonly associated with a younger age e.g. bed wetting, sucking thumb etc.;
- Social responses may include – loss of self-esteem and confidence, withdrawal from friends and activities – including school attendance.

Children may exhibit none, some or many of these responses. All bereaved children and young people have the need for information, explanation and reassurance. Depending on their personalities, the circumstances of the death, family functioning and a child's stage of development, there may be additional needs. Children with intellectual disabilities require special attention to ensure that loss is explained in a way that is appropriate for them and that their experiences are validated (Brickell and Munir, 2008). More generally, children's

needs include help with normalising the experience; help with feelings or behaviours that are disrupting day-to-day life; or, for a very small number, help addressing suicidal thoughts/behaviour and other clinical issues. However the timing of more formal interventions cannot be standardised and depends on the assessment of an individual child's needs (Rosner et al, 2010).

Children's understanding of death

A child's reaction and response to loss is influenced by their developmental phase. 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.

Adults in contact with bereaved children need to keep in mind that the cognitive ability to understand death and bereavement through the essential cognitive processes described above, may not yet have been developed (See Appendix A). Older children and adolescents understand these concepts more immediately in their grief journey but this can present additional challenges as they recognize more quickly the enormity of the loss (Horsley and Patterson, 2006).

It is essential to consider a child's understanding when a death has occurred. Clear and unambiguous language and accurate factual information about the circumstances of the death is important to help children in their understanding. For example, using words like "death" and "died", rather than "gone asleep", helps the child to understand the different elements as described above (Mahon, 1994).

Children's experience of grief and loss is influenced or moderated by a number of factors and some of these are detailed below including family, community, complications in grieving, and long-term consequences of early loss.

Family and support 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). According to Warnick (2015) "The grief experience of children and adolescents does not occur in isolation of those around them. Rather their grief process is influenced by the grief of parents and other primary caregivers, level of family cohesion prior to and following the death, and their immediate caregiving environments".

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). In addition, the complexity of the history of family relationships for the child may lead to the possibility of disenfranchised grieving (e.,g separated families, families with a history of abuse) (Crenshaw & Lee, 2010).

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 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) and have been found to be effective (Bergman et al, 2017). 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).

Communities and culture

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). Family beliefs that have grown over time in relation to the inclusion (or not) of children in bereavement rituals, the recognition (or not) of the impact of grieving on the child, or the long-term effects on the child's life can affect how a child develops appropriate coping strategies around their loss. Akerman and Statham (2014) review the benefits of a whole family approach which by necessity includes cultural context.

Schools, too, play an important role in bereavement care, representing as they do a child's usual 'community'. Nevertheless the best way to provide such support has not yet been determined with a range of reactive, proactive and curriculum-based models in evidence (Akerman and Statham, 2014).

Children's resilience

It is critical for those who are supporting bereaved children to understand that children have abilities to help them to manage and understand change in their lives. They can also be supported to develop attitudes that promote resilience – including hope (Stokes 2009). If the adults who are supporting children can understand and encourage the development of an understanding of the loss, promote normal coping mechanisms and relatively stable environments then the child is supported to develop resilience that will help them through their bereavement.

When grief gets complicated for children and young people

There is now a growing body of research on the depth and breadth of complications for children who are grieving. Dyregov and Dyregov (2012) acknowledge that a proportion of children can experience problems in grieving following parent or sibling loss. Ackerman and

Statham's 2014 review gives a range of 15% of bereaved children being highly vulnerable while up to 40% of the children in families seeking help from bereavement services may have clinical level symptoms. Stikkelbroek et al (2016) review literature which shows up to 25% of adolescents may develop some degree of mental health problem following a close family loss. Rosenberg et al (2015) report increases in anxiety, depression and use of illicit substances among teenagers in the year post bereavement. Further, Foster et al (2012) record findings of reports of personal changes (including personality, school work, goals/life perspective, activities and interests) in 69% of their study population as well as changes in relationships with family and peers in 47% of their study population.

While it is worth reiterating that the majority of children cope well, professionals who work with bereaved children identify the intensity and duration of grief reactions, together with the degree of disruption or functional impairment, as the main characteristics of problem grieving (Dyregov and Dyregov, 2013).

The long-term consequences of childhood bereavement

While the actual loss or death of a person is an 'event', the consequences of the loss is carried from childhood to adulthood. For example, children meet again the loss of a parent at important milestones, anniversaries or transitions such as graduation, weddings, and births (Schonfeld et al 2016).

Recent population studies have begun to show long-term mental health and physical health deficits in cohorts of bereaved children. Li et al, (2014) followed cohorts of people bereaved of a parent in childhood (at age 6 months up to 18 years) and compared mortality rates with the non-bereaved population. Controlling for gender and for socio-economic factors, the researchers found a 50% increased mortality for this parentally bereaved group. Hollingshaus and Smith (2015) also established a long-term mortality risk following early parental death. These associations may vary in strength by the cause of parent's death (e.g. 'natural' or 'sudden/accidental'). Guldin and her colleagues (2015) found an increased long-term risk of suicide in children who has lost a parent during childhood, particularly before age 6.

While this line of research is relatively new, it makes the compelling case for research and a focus on bereavement in national children's policy development in Ireland. With this increased understanding of the immediate, medium-term and long-term effects on children and young people of the loss of a family member, it is critical that the needs of bereaved Irish children are identified and addressed as early as possible.

Appendix C

Self-Assessment Tool for Bereavement Services

	Criteria met	Criteria outstanding	Action required. By whom?
Supports and services have clear, accurate and up to date written information outlining the range of their services and which identifies the level of specific need it can meet.			
A clearly documented model of care.			
All services providing support to bereaved children should have knowledge of contemporary understanding of children's grief and appropriate interventions.			
Services provide information on children's bereavement through leaflets, useful links, websites, information on further reading materials.			
Accessibility of all service levels to all children and families who have experienced bereavement.			
Clearly identified referral pathways at all levels of service provision.			
Use of written consent of parents or guardians for children to access services, and verbal assent from the child who is availing of support.			
Transparent assessment is required to ensure that the service being offered to the child is the most appropriate at that time.			
An assessment procedure that ensures that the child's bereavement needs can be met by the organization.			
A governance structure that clarifies ongoing referral pathway, if the organization find that the child's needs do not fit with the service being provided.			

	Criteria met	Criteria outstanding	Action required. By whom?
Evaluation and feedback procedures and policies for all service stakeholders.			
Records are maintained in accordance with the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003.			
Information obtained by the service pertaining to service users shall be kept confidential.			
A safe process of Recruitment, Selection and probationary period for service personnel.			
Adheres to the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016.			
Adheres to Children First Act 2015 and national Child Protection Guidelines.			
Training and support of all staff and volunteers to underpin the service level provided.			
Individuals involved in supporting bereaved children shall engage in regular professional supervision, Continuous Professional Development and self care activities.			
Persons providing support services shall do so in an ethical manner, in accordance with the Code of Ethics pertaining to their particular profession.			
Agencies shall seek and create opportunities to work collaboratively with other organisations providing support to children and families who experience bereavement			
Organisations shall ensure that all necessary governance procedures are in place to guarantee a transparent service which is run to the highest standards (as set out in 'Your guide to the governance code for community, voluntary and charitable organisations, published by the Department of Education and Skills).			

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