Standards for supporting Bereaved Children & Young People

A FRAMEWORK FOR DEVELOPMENT

Second Edition, 2023

DEVELOPED BY
The Irish Childhood Bereavement Network

proudly supported by TUSLA Irish Hospice Foundation

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 Tusla (The Child and Family Agency) and the Irish Hospice Foundation.

Consultation process:

The first version of these 'Standards' for supporting bereaved children and young people in Ireland were circulated for a wide-ranging consultation process at the end of 2016. Over 60 written feedback forms were received from organisations and individuals, all welcoming the work and providing vital insights and comments. Every effort was made to incorporate the views and comments into the initial 'Standards' document, which was published in 2017.

A commitment was made to update the 'Standards' after 5 years. Hence, this 2023 publication is an updated version of the 'Standards'. A rigorous process was followed in updating the 'Standards' that consisted of: (i) a review of the literature from 2018 to 2023, and (ii) a consultation process with key stakeholders. The update was also informed by the findings of the Childhood Bereavement Services National Survey 2023, which was designed and deployed by the ICBN.

The development of this revised version was supported by ECNE Research, LLC – a company that is committed to providing high quality, medical writing, and clinical research solutions to healthcare organizations to drive faster adoption of evidence and technology, and ultimately improve care and outcomes for patients, clinicians, and institutions.

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Appendices

www.childhoodbereavement.ie

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

Acknowledgements

Sincere gratitude to the key stakeholders who participated in the consultation process for their time and invaluable input, insights, and feedback.

The stakeholders that participated in the 2023 review process were as follows:

- Brid Carroll - Chair of the national advisory panel of the Irish Childhood Bereavement Network (ICBN)
- Estelle McGinley - Senior Social Worker, Milford Care Centre Limerick (member of ICBN national advisory panel)
- Orla Keegan - Head of Education and Bereavement Services, Irish Hospice Foundation (member of ICBN national advisory panel)
- Fionnuala Curry - Children and Young People's Services Committee (member of ICBN national advisory panel)
- Dr. Aoife Lynam - Asst. Professor in Psychology of Education Trinity College Dublin (member of ICBN national advisory panel)
- Anne Staunton - Director of Rainbows Ireland (member of ICBN national advisory panel)
- Sharon Vard - Director Anam Cara parental and sibling bereavement support (member of ICBN national advisory panel)
- Caitriona Curtis - Business Support Manager Tusla (member of ICBN national advisory panel)
- Gina Cantillon - Head of Barnardos Children's Bereavement Service (member of ICBN national advisory panel)
- Eifion Williams - Service Director Tusla
- Dr. Amanda Roberts - National Bereavement Development Coordinator – Irish Hospice Foundation
- Caroline Goulding Brady – Course Coordinator – Professional Certification in Children and Loss (RSCI/IHF)
- Colleen Brown – Barnardos Children's Bereavement Service
- Dearbhla Ni Mhaolagain – Network Support Officer ICBN/IHF

The consultation process was facilitated by Maura Keating - National Coordinator ICBN, and Elizabeth Weathers – ECNE Research, LLC.

Source of Funding / Funding Body

ICBN initiatives are co-funded by Tusla (The Child and Family Agency) and the Irish Hospice Foundation. The 2023 review process was suported by an independent research company and overseen by the national coordinator and the national advisory board.

Conflict of Interest Statement

No competing interests or conflict of interest declared by anyone who participated in this process.

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:

Delineated 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 provide daily care to them. Extended family refers to members of the child's 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.

Foreword

On behalf of the Irish Childhood Bereavement Network (ICBN) I am delighted to present the updated ‘Standards for Supporting Bereaved Children and Young People – A Framework for Development’ 2023. The Standards were initially developed as part of the ICBN’s mission to highlight the needs of bereaved children and young people in Ireland. Since 2014, the ICBN has received core support from Tusla the 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. We are not where we would like to be in providing that support and care yet, but it is important to share these standards are a framework to guide us in our journey and help us recognise when we have arrived. In this way, the standards provide a framework to help us all improve and develop our care for bereaved children and young people.

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.

Since we first published the standards, we have encountered some unique challenges. The full impact of the Covid-19 pandemic is yet to be seen but it greatly affected our resilience and often left feelings of being overwhelmed and exhausted. We know that death anxiety and stress were heightened among children during the pandemic, especially for children who has already experienced a bereavement. The wall-to-wall coverage of death and dying triggered emotions and feelings in bereaved children and young people that were not abstract or something that happens to other people, for them it tapped into pain and hurt because they understood that ‘bad things’ can and do happen to someone you love and if it happened once, it could happen again.

We are committed to remaining focused on the challenge of implementing these standards to ensure that bereaved children are visible so that their needs are not forgotten, lost and overshadowed.

The document has evolved from a wide consultation process, and we thank all those individuals, experts and organisations who have taken the time to provide feedback to us. The ICBN Advisory Panel has been most helpful in their feedback and encouragement along the way, and thanks especially to Brid Carroll (ICBN Chair) and Anne Marie Jones who chaired the working group who developed the first version of the standards in 2017. The review of the standards and this resulting version (2023) was made possible with the expert support and guidance of Elizabeth Weathers and Anna Fraifeld (ECNE Research).

We want this document to be an active support and resource to the childhood bereavement community – that includes all adults supporting children and young people – we can all make a huge difference with non-judgmental compassionate listening support.

Your sincerely,

Maura Keating

National Coordinator - Irish Childhood Bereavement Network (ICBN)

CHAPTER 1

Introduction

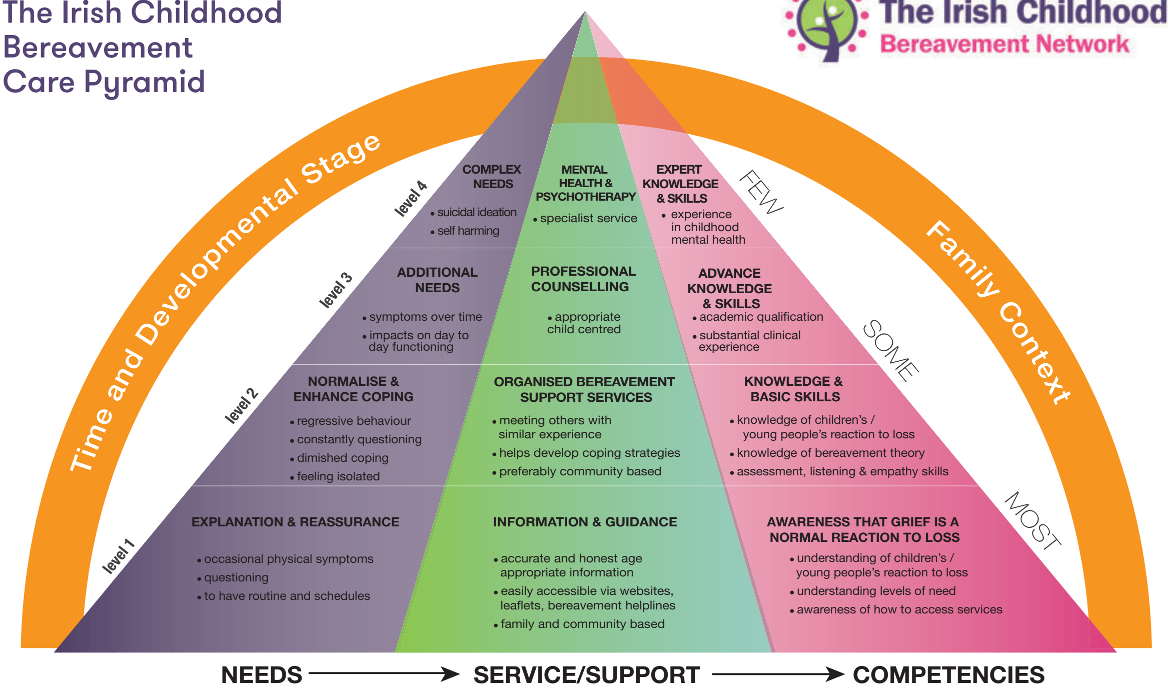
The Irish Childhood Bereavement Network ("ICBN") works to promote the voice of bereaved children and young people, recognising that theirs has traditionally been the silent voice of grieving. The recognition that children's grieving is similar to, but not the same as adults', is not yet widely understood. 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 is it 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. New literature in Scotland and the United Kingdom has identified that over half of all children are bereaved of a parent, sibling, grandparent, or other close family member by age 8 and this increases to 62% by age 10. Children's loss 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 additional learning needs;
- The primary support for children and young people who are grieving is their family or someone who is well-known to the child;
- 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 personal history, 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 such as suicide, for example, often involves trauma for the children and young people concerned. Children bereaved by a suicidal death are particularly vulnerable to short- and more intense long-term consequences of grief. 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 have examined the long-term effects of bereavement on children and young people when they are adults have reported some long-term physical and mental health consequences well into later life for those bereaved of a parent or sibling in childhood (see literature review report in Appendix B and please refer to the section on long-term consequences of childhood bereavement).

The Irish Childhood
Bereavement
Care Pyramid



www.childhoodbereavement.ie/pyranid

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.

The Pyramid helps any individual (family and professionals) to identify their own responsibility and importantly, to be aware of others who can provide more support if this is required.

1. **LEVEL ONE:** aimed at family and adults in the child's natural network.
   This relates to the majority of chidren

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2. **LEVEL TWO:** aimed at bereavement support organisations in local areas including schools, faith-based and community services.
   This relates to only some children

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3. **LEVEL THREE:** advises those in professional counselling settings.
   This relates to only some/few children

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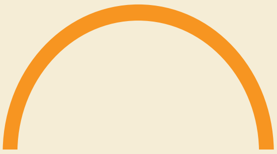
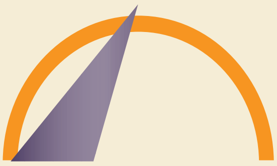
4. **LEVEL FOUR:** addresses mental health professions.
   This relates to very few children

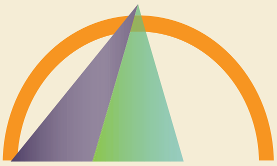
How to use the Pyramid



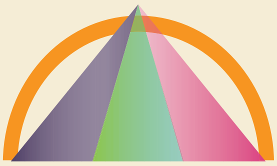
The **arc surrounding the Pyramid** demonstrates that the care of children and young people must be approached in a family context (consider the strengths, pressures and functioning of family life). The arc also pays attention to the passage of time, and the child's ongoing development. The meaning and implications of loss can be ever-present and worked through at each new milestone in the child's life e.g., first day at secondary school, first date, first job.



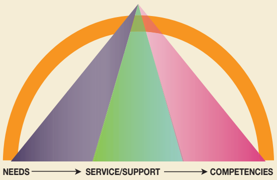
The **purple** segment identifies the needs of bereaved children and young people from basic to advanced.



The **green** segment identifies the appropriate support or service required to respond to these needs.



The **pink** segment identifies the type of competence responders should possess.



The **base** of the pyramid is relevant to most bereaved children. As the levels ascend, the needs become increasingly more complex – as do the required responses and competences.

In revising this Standards document, consideration was given to the alignment between the ICBN Pyramid and each of the individual Standards. Further information on how the Standards are applicable at each level of the pyramid is provided in **Appendix C**.

Developing the Standards

In 2017, the ICBN developed "Standards for Supporting Bereaved Children and Young People" and this work has been updated in this document. Updating the Standards in 2023 included an extensive review of the academic literature and a review of the grey literature (see literature review report in Appendix B). Relevant literature sourced was integrated into the Standards document. The updated Standards were then circulated to an advisory and stakeholder committee for review, and two consultation meetings were held.

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 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 level.

> **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 are not clinical practice guidelines but instead provide a guiding framework to help us all improve and develop our care.**

Rigor in the development of these standards

While these standards were not designed to be clinical practice guidelines, a rigorous and transparent process was followed in the development and update of the Standards. This included a clear description of stakeholder involvement, a description of the strategy used to update the literature review, evidence selection criteria, and link between recommendations and evidence (see Appendix B and D for further information).

The Standards

Standard 1	**Child and Young Person**: *Children's experience of bereavement will be recognised, acknowledged, and supported in accordance with their needs over time.*
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.*
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 as needed, based on new significant evidence or substantial changes in the context of childhood bereavement. The methodology for a future update should at a minimum include an extensive literature review and consultation with the advisory group.

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, health care staff, youth and community professionals. 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 with including 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.

Using these Standards as a guiding framework, you will be able to plan and develop your service, review your practice with confidence, and identify knowledge gaps and educational needs knowing that the framework is based on an extensive evidence base.

1. Planning – Standards may be used to:

- Promote a national “vision” for and shared understanding of children’s bereavement care in Ireland;
- Inform education and training of professionals who will be in contact with bereaved children
- Direct the ways in which communities, families, service providers and policy planners can promote resilience and provide support for bereaved children;
- Shape investment in bereavement care and to develop funding applications;
- 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;
- Ensure that bereavement support for children is based on the latest international findings in the field of children's bereavement care;
- 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;
- Demonstrate strong and transparent governance through self-assessment;
- Ensure that the family is seen as central to the support provided to children and are supported appropriately;
- Ensure that service providers adhere to the best international standards in their work;
- 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;
- 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.

CHAPTER 2

Standard 1
Child and young person

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

Rationale

Reactions to loss and bereavement vary among children. 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 over 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 take cognisance of the circumstances of their bereavement and family functioning. Childhood bereavement experts recommend that support should also be offered on an ongoing basis, with built-in flexibility to meet individual needs.

Timing of delivery of support is an important factor – strategies to support children through bereavement should be initiated closer to their loss experience and should include people who were well known to the child before the loss, such as family members or even the school environment. Any intervention should have the appropriate consent of parents/guardians.

Children's reactions to bereavement

Following a death, children can experience various grief reactions, such as:

- Psychological responses – fear, anxiety, confusion, anger, sadness, relief, loneliness, guilt, isolation, neuroticism, phobia, panic, depression;
- Physical responses – low energy, interrupted sleep/eating patterns, unexplained aches, pains;
- Behavioural responses – 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 – loss of self-esteem and confidence, decreased perception of performance, withdrawal from friends and activities, including school attendance, learning difficulties.

Children may exhibit none, some, or many of the above responses. Most children and young people can manage their bereavement appropriately with the support of their family.

All bereaved children and young people have the need for information, explanation, and reassurance. Older children 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.

Children and young people may have difficulty understanding bereavement, and this leads to a wide range of reaction symptoms. It is essential to consider a child's understanding when a death has occurred, check what they understand about death, do not assume that they can infer meaning in the way that adults do. Clear and unambiguous language and accurate 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.

> **You just have to remember that communication is the most important thing...and you have to talk about it...so that you don't feel like you need to keep some things secret or that there are some [things] you are not allowed to talk about. (Freja, 14)**
>
> (Quote from a child participant in Lytje, 2016)

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 honest, 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 support 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.

What will success look like?

✓ Children and the adults in their lives have an awareness of how children understand grief and have knowledge of 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.

Alignment with Irish Childhood Bereavement Care Pyramid

Standard 1 pertains to children and young people at an individual level, which is at the core of the Irish Childhood Bereavement Care Pyramid. In determining an individual child's needs, consideration should be given to the developmental stage, family context (availability of family support), and timing of any intervention.

Remember most bereaved children may exhibit level 1 or level 2 needs and require explanation and reassurance from a trusted person in their lives who understands children's reaction to loss and is aware of how to access organised bereavement services. Fewer children and young people will exhibit level 3 or level 4 complex needs and therefore, require advanced or expert knowledge with mental health or psychotherapy interventions. After identification of a child's level of need, it is essential to identify the level of service or support they may require.

CHAPTER 3

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, empowering the family is an essential part of supporting a bereaved child or young person. The family's strengths 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 able 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 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. Children report that the most helpful types of support came from people who were well known to them before their loss, from those compassionate listening non-judgemental adults.

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 the key source of support for bereaved children and need to be empowered with knowledge and information to provide the best support possible at these challenging times. It is equally important that adults supporting children obtain their own support to help them deal with grief - in doing so the outcomes for children will also be enhanced.

Families are in a key position to address the needs of bereaved children. Strong family cohesion has been reported to decrease long-term negative outcomes for bereaved children and young people. However, parents and carers can, at times, be so overwhelmed by their own grief that parenting and supporting children can feel like a struggle. For children, relationships with their parents can change, the family restructures itself, and their individual and family needs may not be met in the same ways, with strain on relationships. 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.

Some parents may struggle to find appropriate professional bereavement support and report a mismatch between needs and the help provided, with some professionals not equipped to deal with their needs or situation. 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. In fact, some children even modify their behaviour and try to be 'good' to prevent their parents from becoming upset or do more to help their surviving parent. Others suppress their emotions and feel isolated, as if they are grieving alone. 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.

> **My first advice would be don't hide it. It is too heavy a burden to carry alone. And you should not have to. Don't be afraid to say what you need, but also what you don't need. Be open about it; that is the best advice I can give. Because people do want to help, but they often struggle knowing how to.**
>
> (Quote from a parent participant in Lytje and Dyregrov, 2023)

Criteria to demonstrate the Standard has been met

2.1	Families and caregivers have access to information, literature and guidance on how children understand death 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 resources and support services and play a key role in deciding the most appropriate services, for their children, if needed.
2.3	Counselling or other support provided directly to a child is deemed to be complementary to any support provided to the child by the family.
2.4	Families in need of external help 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 support as needed.
- Children feel included in the family's bereavement.
- 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 provided by families, rather that it supports and enhances same.

What will success look like?

- ✓ 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 sources of bereavement support.
- ✓ Key adults recognise that children sometimes need support outside the home.
- ✓ Key adults have access to support and guidance that is specifically tailored to enable them to support the bereaved child(ren).
- ✓ There is information and support to address families experiencing sudden and/or traumatic death.

Alignment with Irish Childhood Bereavement Care Pyramid

The family context and ability to provide support is crucial in supporting a bereaved child or young person. Families are the key source of support for bereaved children and need to be empowered with knowledge and information to provide the best support possible at these challenging times. It is equally important that adults supporting children obtain their own support to help them deal with grief - in doing so the outcomes for children will also be enhanced.

Where family cohesion is strong and support is readily available within the family, most children will benefit from explanation and reassurance provided at level 1, including the opportunity to talk about their bereavement experience with a trusted person in their lives.

If it is determined that family support is limited or hindered in any way, this may elevate the needs of the child or young person from level 1 to level 2, and services and support levels will need to be adjusted to optimise bereavement care.

For those with more complex level 3 or 4 needs, family involvement has been proven to be beneficial in participation with psychotherapy and bereavement supports. In order to support children and young people, family members must have an awareness that grief is a normal reaction to loss, and have knowledge and basic skills in assessment, listening, and empathy.

CHAPTER 4

Standard 3
Local Community

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

Rationale

In Ireland, community support is arguably one of the most important pillars in childhood bereavement but this needs to be further developed. Members of a bereaved child's community have the opportunity to interact with, and closely support, a grieving child once they have been empowered to do so.

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. The most helpful types of support came from people who were well known to children before their loss. A wide range of community support areas include, but are certainly not limited to, schools, churches, community centres, libraries, and sports clubs.

Normalising experiences with bereavement are frequently identified as essential to a child's grief. Often, this comes from cohorts their own age. Children and young people can feel more secure speaking with close friends, with less worry of being teased or hurt. Parents and trusted adults within a bereaved child's life must understand the implications of childhood relationships and their potential role in educating their child on supporting a bereaved friend.

An essential member of community support is an educational-based environment. Children highlight school as a good source of support. Naming that it feels like a safe place, provides a sense of belonging, routine and is an emotional escape through extracurricular activities. However, it is also 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.

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.

> **My situation was often taken into account and how I was feeling and things like that and of course, the teachers approached me and...asked how I was doing and said that they were sorry about what had happened ... They were very considerate of my situation. (Siv, 15)**
>
> (Quote from a child participant in Lytje, 2016 – when asked what was most important during their return to school, it often centred on the class and teacher showing some understanding of their experience.)

Criteria to demonstrate the Standard has been met

3.1	→	At a minimum, information about children's bereavement and support should be available in local 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 training advice and information services/phonelines.
3.3	→	Children will always be given the opportunity and choice to be included in local bereavement events and rituals.
3.4	→	Specialist services for children experiencing complications (Level 4 on bereavement care 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 acknowledge and understand their bereavement.
- Children can get support in their local community, either informally or through services.
- Those children with complex bereavement needs are recognised and communities have clear referral pathway to access appropriate qualified professionals (in a prompt fashion).

What will success look like?

- ✓ Bereavement training and networking opportunities are open to community services supporting bereaved children and young people.
- ✓ The services of national organisations are accessible locally, including telephone and one-to-one support.

Alignment with Irish Childhood Bereavement Care Pyramid

Standard 3 on community support aligns with level 1 and 2 of the pyramid in terms of needs, services / support required, and competencies necessary for those delivering the support. ‘Most’ or ‘some’ children will exhibit needs that can be fully met by their family and community via information and guidance, and organised bereavement support services.

Information for bereaved children may be identified via websites, leaflets, and helplines within their community. Potentially, there are community members who have had similar experiences and can assist in developing coping strategies. Most children and young people spend a lot of time in school and therefore, having access to support within their school from teachers and others is paramount.

For those providing support at a community level, it is important to have basic knowledge and skills including knowledge of bereavement theory, awareness of children and young peoples’ reactions to loss, and skills in assessment, listening, and empathy. Community based support can enhance coping skills and diminish feelings of isolation.

CHAPTER 5

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 bereavement. Some of the personal changes reported by adolescents include personality, schoolwork, 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. Professional support comes from a wide range of adults including counsellors, psychologists and healthcare professionals.

These services are seen by children as helpful when they are being honest with them, checking on their well-being, helping them develop coping strategies, being open and flexible to their needs, and being available quickly.

A consensus statement from childhood bereavement experts recommended that support should also be offered on an ongoing basis, with built-in flexibility to meet individual needs. Some examples of support services include group sessions, which were most-frequently identified, individual and family therapy, telephone support, conferences, and onward referral programs. These interventions focus on sharing and expressing loss, grief education, maintaining relationships and memories, learning coping skills and methods of self-reflection.

Individuals or services providing formal support must operate according to standards of best practice as set out below. It is recommended that each provider review their service, its governance and engage in continuous improvement. In addition, individuals working in an organisation or alone should be accredited by the relevant professional or national body. A self-assessment tool is provided in Appendix E that you can use to review your service, its governance and engagement in continuous improvement.

According to findings of the recent ICBN Childhood Bereavement Services National Survey (2023), childhood bereavement supports in Ireland are mainly integrated into existing services for children and families with a small number of stand-alone childhood bereavement services. Almost half of the services are provided by voluntary community-based organisations (e.g., family resource centres, youth and community centres, domestic violence projects, one parent family groups) or schools. Services are also provided by healthcare, statutory, and private organisations, as well as by individual practitioners. This makes for large variation in service delivery.

To ensure quality services in all regions bereavement services for children and young people should be:

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

Criteria to demonstrate the Standard has been met

The criteria for service providers has been categorised into two sections: (i) Service providers that are registered charities, and (ii) All service providers.

4.1 **Any registered charity organisation providing bereavement services to children should ensure that their governance structure includes:**

4.1.1 All necessary governance procedures are in place to guarantee a transparent service which is run to the highest standards (as set out in the Charities Act 2009 and any future amendments or updates to charity regulation legislation).

4.1.2 Policies and procedures to ensure that records are maintained in a confidential manner in accordance with the Data Protection Act (2018) and the Freedom of Information Act 2014.

4.1.3 Adherence to the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016.

4.1.4 Adherence to Children First Act 2015 and National Child Protection Guidelines.

4.1.5 Adherence to relevant national regulatory requirements, including those outlined above and all other requirements relevant to your organisation.

4.2 **All organisations (or private practitioners) providing bereavement services to children should ensure that their governance structure includes:**

4.2.1 Clearly document the model of care within your service.

4.2.2 Clear, accurate and up to date written information outlining the range of services and identifies the level(s) of specific need it can meet.

4.2.3 Knowledge of contemporary understanding of children's grief and appropriate interventions.

4.2.4 Provision of information on children's bereavement through leaflets, useful links, websites, information on further reading materials.

4.2.5 Clearly identified referral pathways to all levels of bereavement support offered by a service provider and structure of referral if the provider finds that child's needs do not align with the services they provide.

4.2.6 Written consent of parents or guardians for children to access services and verbal assent from the child who is availing of support.

4.2.7 Transparent assessment of the child's bereavement intervention needs to ensure that the service being offered is the most appropriate at that time and can be met by the service provider.

4.2.8 Evaluation and feedback policies and procedures.

4.2.9 An awareness of the limitations of confidentiality when working with children.

4.2.10 A safe process of recruitment, selection and probation for service personnel and volunteers.

4.2.11 Training and support of all staff and volunteers to underpin the service level provided.

4.2.12 Regular professional supervision, Continuous Professional Development, and self-care activities for all individuals involved in supporting bereaved children.

4.2.13 Providing support in an ethical manner, in accordance with the Code of Ethics pertaining to their particular profession.

4.2.14 Agencies shall seek and create opportunities to work collaboratively with other organisations providing support to children and families who experience bereavement.

4.2.15 Adherence to relevant national regulatory requirements, including those outlined above and all other requirements relevant to your organisation.

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.

What will success look like?

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

Alignment with Irish Childhood Bereavement Care Pyramid

Service providers fall within all levels of services and support of the Irish Childhood Bereavement Care Pyramid. They are equipped to provide information and guidance, organised bereavement support services, professional counseling, and mental health and psychotherapy.

They are especially essential in supporting those ‘few’ children and young people with level 3 or 4 needs, where family and community support is not sufficient. Even more important is that services providers also fall within every level of competencies and should have staff with advanced and expert knowledge and skills.

CHAPTER 6

Standard 5 National

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

Rationale

Children are not immune from the impact of bereavement, and it is a global issue. 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. New literature in Scotland and the United Kingdom has identified that over half of all children are bereaved of a parent, sibling, grandparent, or other close family member by age 8 and this increases to 62% by age 10. In the United States, there are nearly 5.6 million bereaved children and teens, with almost 8%, or 1 in 13, experiencing the death of a parent or sibling by age 18.

While the actual loss or death of a person is an 'event', the consequences of the loss can extend beyond childhood to adulthood. The most reported long-term consequences are prolonged grief disorders or depression. Studies report that 10-18% of parentally bereaved young people demonstrate persistently maladaptive grief reactions over the course of 33 months after the death. Meanwhile, parentally bereaved adolescents have a higher risk of self-injury 6-9 years post-loss. Additionally, children who experienced a sudden parental death (e.g., suicide or accidental death) had a significantly reduced likelihood of completing all educational levels compared to children who did not have such experiences. 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.

A growing body of evidence has shown that acknowledging and providing appropriate support to bereaved children and their families has a positive effect on their wellbeing and health, including minimising the chance of long-term consequences. This means that it is essential to adopt a public health approach to bereavement and its consequences.

Consequently, it is critical to:

- develop a coherent national childhood bereavement policy that takes account of supports needed by families at times in their life when they experience bereavement;
- promote positive mental health and develop services nationally in order to minimise 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.

According to findings of the recent ICBN Childhood Bereavement Services National Survey (2023), three key implications and next steps for childhood bereavement support services were highlighted: (i) expand and build upon current support systems; (ii) enhance knowledge and training of those currently responding to the needs of bereaved children; and (iii) facilitate knowledge sharing to promote consistent referral pathways for bereavement supports and to improve access to evidence-based resource material. This Standards document provides guidance to all stakeholders in support of appropriate governance and service provision.

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 working with children and families to 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?

- Bereaved children's needs are legitimised and recognised 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.

What will success look like?

- ✓ Bereaved children will have equitable access to required support 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.

Alignment with Irish Childhood Bereavement Care Pyramid

The Irish Childhood Bereavement Care Pyramid and these Standards provide a foundation for the development of policy and strategy at a national level, which should consider needs, services and support, and competencies at all levels (individual, family, community, service provider, and national). In terms of competencies, national policy should delineate structures and an implementation plan for bereavement education at community and service provider levels.

Appendix A

Introduction

Approximately 80 people die every day in Ireland. They are parents, grandparents, aunts, and siblings – bereaved children can often be invisible. 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. Some families may not be able to provide this support if the bereavement has impacted them in a way that does not allow them to draw on sufficient resources to provide that support.

Children express grief differently and often need help to understand the complexity of emotions. Talking openly using clear and concrete language helps, breaking information down to the level of the child's understanding and being prepared to repeat the information in a reassuring way is a key component of childhood bereavement support.

Children's Understanding of Death

In order to develop services and support methods for children and young people, we must first develop an awareness of children's grief, and their understanding of grief. It is essential to explore age-related changes that children and young people experience as they cope with bereavement.

The way children understand and react to grief depends on their age and stage of development. As they grow and mature, their understanding of death increases. For example, very young children do not understand death but feel the absence of the familiar person that has died, they can sense that something has changed but operate in the present once routine is maintained. Young children do not understand that death is final and may search for the person. For preschool aged children and those in early primary school death is often seen as reversible, not permanent: "Did you know my Mum died? When will she be home?" At this age children are magical thinkers and may feel responsible because of wishes and thoughts. Common statements include: "It's my fault. I did not eat all my vegetables."

Every child is different but at some point, (usually in middle childhood), they begin to fully understand the concept of death in a more mature way, however some neurodiverse children may not grasp the full extent that death is final. Giving all children the opportunity to be involved in goodbye rituals can help them with their grief journey as it can give them a sense of control at a difficult time.

Children's understanding depends on age and development stage:

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 information are general and may help you:

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

Grief reactions in preschoolers are similar regardless of the cause of death and can be expressed predominantly through changes in behaviour and play. Confusion around the deceased absence, anger, intense sadness, regressive behaviours (e.g., bed wetting), increased caregiver dependency, and sleep disturbances were common manifestations in this age group. 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

School-aged children can experience a wide range of positive and negative manifestations of separation distress. 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. School-aged children experience sadness, longing for the deceased, loneliness, anxiety, depression, intense anger, and fear of death alongside happiness and personal growth. It can help children if they are encouraged to talk about and express their feelings, no matter what the feelings are. School-aged children may try to make a connection with the deceased by wearing their clothes, sleeping in their bed, dreaming about them, or talking with them. More curious children in this age group often ask direct questions about what has happened to the body as they try 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

Children in this age-group 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. It can help to provide regular opportunities for children to talk and share their feelings, while offering support and reassurance.

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. 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. Adolescents may experience rage, denial, anger, loneliness, despair, sadness, helplessness and crying over the physical separation. Adolescents also exhibit maladaptive coping mechanisms such as substance use, suicidal ideation, risk-taking behaviours, and stagnancy of psychosocial development.

For more details and information on what to expect visit Children and Grief by Age and Stage - Irish Childhood Bereavement Network.

Appendix B

Literature Review Report

Aim of Search

The aim of this standards update was to review recent literature on supporting bereaved children and young people and to utilise findings from the review to update the Irish Childhood Bereavement Network (ICBN) 'Standards for Supporting Bereaved Children and Young People' (the 'Standards').

A review of the literature was conducted in the following electronic databases:

- PubMed: this database comprises more than 34 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full text content from PubMed Central and publisher web sites.
- Cochrane: The Cochrane Library is a collection of databases that contain different types of high-quality, independent evidence to inform healthcare decision-making. The Cochrane Library is owned by Cochrane and published by Wiley.

A review of the grey literature was also conducted to supplement the database search. This search included relevant national and regional health policies, working papers, international standards and guidelines, and a search in Google, Google Scholar, www.greynet.org, and other sites deemed relevant by the project management team.

The review questions were as follows:

1. What is the prevalence of childhood bereavement in Ireland, Europe and globally?
2. What is documented in the literature regarding children's typical reactions to bereavement and children's understanding of death?
3. What family and community factors influence children's perceptions of bereavement?
4. What is documented in the literature about resilience and complicated grief in bereaved children and young people?
5. What supports and services have been proven effective for children?
6. What are the long-term consequences of childhood bereavement?
7. What other similar policies, guidelines, and standards exist at a national level?

Search Terms and Selection Criteria

A combination of the following key search terms was used: bereavement, grief, children, child, adolescents, teenagers. Boolean operators (e.g., AND, IF, NOT) were used to broaden or narrow the search. The search was limited by publication year (2018-2023) and language (English).

The search strategy was built around the following key search concepts / strings:

- Concept 1 = Bereavement
- Concept 2 = Children
- Concept 3 = Support
- Concept 4 = Policies

An overview of the key search concepts / search strings and search terms used is provided in Table 1 below:

Table 1. Search Concepts / Strings

Concept 1	Bereavement	bereavement OR grief
Concept 2	Children	childhood OR child OR adolescent OR teenager
Concept 3	Support	support OR interventions OR services
Concept 4	Policy	Policy OR guideline OR procedure OR protocol OR standard

The search concepts were combined as follows:

- Concept 1 AND 2 AND 3 NOT (perinatal OR psychiatric)
- Concept 1 AND 2 AND 4

The PICOC framework was used to guide inclusion / exclusion criteria (see Table 2 below).

Table 2. PICOC framework guiding the selection criteria

Population	Children and young adults accessing and receiving bereavement support services in the community
Intervention	Bereavement support and care
Comparator	N/A
Outcomes	Reactions to bereavement, resilience, long-term consequences
Context	Bereavement of a close family member

Grey Literature Search

Searches of the grey literature resulted in 8 policy and guideline documents, along with 1 relevant website.

Search Results

Searches in the academic databases resulted in 54 included articles. An overview of the search process and results is provided in the PRISMA flow diagram in Figure 1 below.

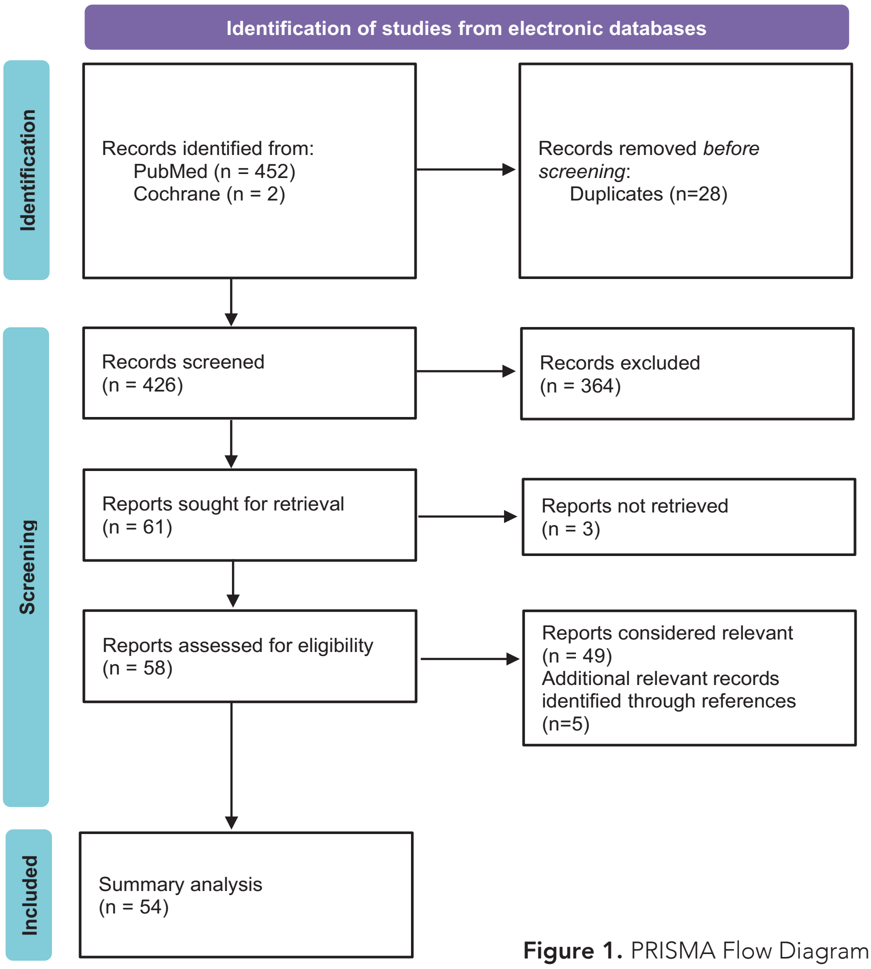


Figure 1. PRISMA Flow Diagram

Searches of the grey literature resulted in 8 policy and guideline documents, along with 1 relevant website. An overview of grey literature search results is provided in Table 3 below.

Table 3. Overview of results from grey literature searches

Resource / Document	Comment on search results
Greynet / OpenGrey	No
Google Scholar	None additional not already included in literature search
Google	Yes (many additional international organisations standards identified; 8 documents relevant and utilised; 1 website)

A narrative approach was taken to synthesize results. The narrative summary was guided by the following key headings:

- Prevalence of childhood bereavement
- Children's understanding of death
- Children's reactions to bereavement
- Family and support context
- Communities and culture
- Children's resilience
- Complications of grief
- Long-term consequences of childhood bereavement

Literature Review Results

Prevalence of childhood bereavement

Many children will experience bereavement. Childhood bereavement is a growing topic of interest, as evidenced by the recent reviews that identify the increasing number of adolescents and children who experience loss and grief. 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 and Morgan, 2012). Previous reports suggest that 30% of adolescents have experienced at least one sudden loss in their lifetime (Schonfeld and Demaria, 2018). However, new literature in Scotland and the United Kingdom has identified that "50.8% of all children are bereaved of a parent, sibling, grandparent or other close family member by age 8 and this rises to 62% by age 10" (Paul and Vaswani, 2020). Additionally, 11% of children and young people report an exposure to a suicide death, and 62% report exposure to a non-suicide death (Del Carpio et al., 2021).

In the United States, there are nearly 5.6 million bereaved children and teens, with almost 8%, or 1 in 13, experiencing the death of a parent or sibling by age 18 (Delaney, 2022; Burns et al., 2023). However, there are geographical areas where urban and suburban children and young people are more likely to lose a parent before 18 (Burns et al., 2020). Similarly, minority subpopulations such as Black and Indigenous Americans, LGBTQ+ and low-income household children are reported to experience a disproportionate amount of bereavement and familial loss (Burns et al., 2020; Paul and Vaswani, 2020; Ryan et al., 2022; Harden et al., 2021). These results have become even more pronounced since the COVID-19 pandemic (Burns et al., 2020). Prior research shows that the incidence of childhood bereavement is on the rise. Thus, active efforts should be made to understand the implications of childhood and adolescent bereavement and to better assist these children and young people in managing grief.

Children's understanding of death

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

A child's understanding and response to death 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 things 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 may not yet be 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 recognise 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. All bereaved children and young people have the need for information, explanation, and reassurance. Clear and unambiguous language and accurate 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). There may be additional needs depending on a child's personality, the circumstances of the death, family functioning and stage of development. 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 usually require 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).

In summary, children and young people may have difficulty understanding bereavement, and this leads to a wide range of reaction symptoms (Watson et al., 2021).

Children's reactions to bereavement

Studies consistently suggest that external factors in the child's environment influence how they react to bereavement and grief (Sasser et al. 2019). Some of these factors include support from family and friends, circumstances of the death, communication and openness with support systems, caregiving environment, how other family members respond to grief, the availability of a primary attachment figure, their school environment and the training of teachers and peers, socio-economic status (Azuike et al. 2022; Birgisdóttir et al. 2023; Jessop et al. 2022; Revet et al. 2021; Schaefer et al. 2022; Woodward et al., 2023; Wray et al. 2022).

Additionally, internal factors also impact a child's bereavement. These may include their personality, age, age at the time of loss, religious beliefs, developmental stage, overall maturity, previous experience with death and grief, their relationship to the deceased person, culture and race/ethnicity and their typical emotional responses and ability to manage change (Birgisdóttir et al. 2023; Revet et al. 2021; Jessop et al. 2022; Wray et al. 2022) (see Figure 2 below).

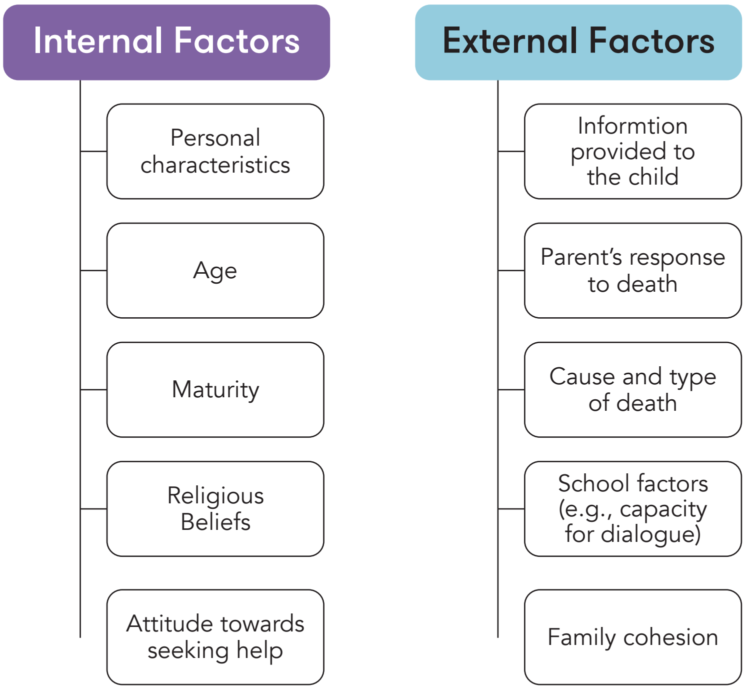


Figure 2. Examples of Internal and External Factors Influencing Children's Reactions to Bereavement

In a large study of bereaved children in the 1990's, Worden and his colleagues provided empirical evidence that children do indeed grieve and 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 movement 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 and 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).

Following a death, children can experience various grief reactions. Children may exhibit none, some, or many of the following responses:

- Psychological responses may include – fear, anxiety, confusion, anger, sadness, relief, loneliness, guilt, isolation, bipolar episodes, phobia, panic, depression;
- 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, decreased perception of performance, withdrawal from friends and activities, including school attendance.

(Farella Guzzo and Gobbi, 2021)

Farella Guzzo and Gobbi (2021) also reported that behavioural reactions amongst adolescents were predominantly negative. Behavioural reactions to grief included crying, anger, shock, psychiatric hospitalisation, and engagement in riskier sexual activity (Farella Guzzo and Gobbi, 2021). Some subjects experienced the onset of significant and new problems which included depression, alcohol abuse, delinquency, threatened school failure, and in some cases, suicidal ideation (more likely after the death of a parent). The experience of losing a parent may negatively affect coping behaviours later in their adult years. Major depressive disorder as well as anxiety disorder were amongst the most prevalent mental disorders following parental loss (Farella Guzzo and Gobbi, 2021). It is important to note that studies assessed in this segment are limited to surveyed populations and should not be generalised to all bereaved children.

Social impacts can include decreased perception of self-performance, delinquency, failure to be promoted, decreased ability to focus and adjustment issues in school. Some adolescents who had lost a parent tried to replace the deceased parent with household responsibility to help the surviving parent, a reaction known in pediatric psychiatry and psychology as child parentification. This leads the adolescent to take on greater responsibilities than his/her age and maturity typically does, and in a specific socio-cultural context leading them to assume the role of the parent for the widow parent. This coping strategy can have serious consequences for the adolescent's development and their future relationships (Farella Guzzo and Gobbi, 2021).

Children's experience of grief and loss can be influenced or moderated by several factors and some of these are detailed below including family, community, children's resilience, complications of grief, 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 and Patterson, 2006; Wender, 2012), as adults who surround them may not understand the child's need to grieve or are affected by their own loss to the extent that they are 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 and 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 and 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 strengthening their abilities to offer support to their children (Morris, 2012). However, in some circumstances, the situation surrounding the death can result in the parents and families feeling alienated within their community (Saunders, 1995) and therefore, make it more difficult to seek support. Moreover, the general literature on parents' help-seeking behaviours shows that a perception of stigma can account for a large proportion of families avoiding help (Dempster et al, 2013).

Most children will develop 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 make it difficult for them to provide such support, outside interventions may be required and have been found to be effective (Bergman et al, 2017; 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).

Communities and culture

Attention should be paid to the complexities of a 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.

Schools also play an important role in bereavement care, representing a child's usual 'community'. During adolescence, peer and school support are argued to be one of the main support groups (Farella Guzzo and Gobbi, 2021; Schonfeld and Demaria, 2018). For example, school psychologists are intertwined in this community support system. They are not only able to identify, and assist with, the needs of bereaved children but can also provide guidance to schools, educators, parents, and peers (Schonfeld and Demaria, 2018). Support from teachers and friends can also enhance the support children receive from parents and facilitate the bereaved child's adjustment (Schonfeld and Demaria, 2018). Literature supports the return of children to school soon after the death of a loved one. Therefore, it is essential that children are met with substantial support in this environment (Morell-Velasco et al., 2020).

Yet, school support structures and responses to the needs of a bereaved student can be inconsistent. Teachers and classmates often do not know how to treat grieving students, which can lead to many grieving children or young people feeling isolated, ignored, and alone at school (Morell-Velasco et al., 2020). This is underpinned by the fact that only a small percentage of educators' report that they have had any training on assisting grieving children and this lack of training is the primary reason they avoid reaching out to and supporting grieving students in their class (Schonfeld and Demaria, 2018). Teachers exhibit great variability in reactions to having to deal with death-related issues with their students, including discomfort and lack of skills and competencies. In a survey developed by ICBN with input from the Children and Young People's Services Committees (CYPSC), information was gathered on the range of services and support available for bereaved children and families in Ireland. In this survey, only 58% of respondents identified that they had ever received training on grief and bereavement in children (ICBN, 2023). Additionally, nearly 13% of 103 organisations reported that they had no level of training in bereavement and grief. Unfortunately, the best way to provide support has not yet been determined with a range of reactive, proactive, and curriculum-based models highlighted in the literature (Akerman and Statham, 2014). Therefore, there is a need for specific education on grief and loss for schoolchildren, as well as specific training of teachers in emotional skills and emotional support at both primary and secondary school levels (Morell-Velasco et al., 2020). This is an opportunity to improve bereavement support within the school systems, which is a pivotal part of community for children and young people.

Children's resilience

It is critical for those who are supporting bereaved children to understand that children have innate abilities and attributes that can help them to manage and understand change in their lives. They can be supported to develop attitudes that promote resilience – including hope (Stokes 2009). If 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 could develop their own resilience that will help them through their bereavement and prepare them for future life events.

Complications of grief

There is now a growing body of research on the depth and breadth of complications for children who are grieving. Dyregov and Dyregov (2012) acknowledged that a proportion of children can experience problems in grieving following parent or sibling loss. Ackerman and Statham (2014) reported that 15% of bereaved children are highly vulnerable while up to 40% of children in families seeking help from bereavement services may have clinical level symptoms. Stikkelbroek et al. (2016) found that up to 25% of adolescents may develop some degree of mental health problem following a close family loss. Rosenberg et al. (2015) reported increased anxiety, depression, and use of illicit substances among teenagers in the year post bereavement. Furthermore, Foster et al. (2012) recorded personal changes (including personality, schoolwork, 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 most children cope well, professionals who work with bereaved children highlight that the intensity and duration of grief reactions, together with the degree of disruption or functional impairment, are the main characteristics of problems with grieving (Dyregov and Dyregov, 2013).

Long-term consequences of childhood bereavement

While the actual loss or death of a person is an 'event', the consequence of the loss can extend beyond childhood into adulthood. For example, children can be reminded of their loss on important milestone dates such as anniversaries, or during transitions such as graduation, weddings, and births (Schonfeld et al 2016). Reportedly, victims of childhood bereavement can experience long-term effects of negative psychological outcomes, self-injury, increased psychological distress, unresolved grief, anxiety, and self-harm (Jessop et al., 2022). The most reported long-term symptom is prolonged grief disorders or depression (Revet et al., 2020. Alvis and colleagues (2022) suggest that 10-18% of parentally bereaved children and young people demonstrate persistently maladaptive grief reactions over the course of 33 months after the death. Likewise, another study reports that peritraumatic distress is a predictor of prolonged grief disorders ($p<.01$) (Revet et al., 2021).

Population studies have highlighted 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 (from age 6 months up to 18 years) and compared mortality rates with a non-bereaved population. Controlling for gender and for socio-economic factors, the researchers found a 50% increased mortality in the parentally bereaved group. Hollingshaus and Smith (2015) also established a long-term morality risk following early parental death. These associations may vary in strength depending on 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 had lost a parent during childhood, particularly before age 6. Similar findings were noted in a more recent study where children with poor family cohesion had a higher risk of reporting symptoms of moderate to severe depression (31.6% poor vs. 8.6% good; RR: 3.67, 95%CI: 2.50–5.40), low levels of well-being (36.4% poor vs. 15.9% good; RR: 2.28, 95%CI: 1.68–3.10), symptoms of anxiety (RR: 2.32, 95%CI: 1.64–3.29), problematic sleeping (RR: 1.80 95%CI: 1.30–2.48), and emotional numbness (RR: 2.86, 95%CI: 1.91–4.30) six to nine years after the loss compared to those reporting good family cohesion (Birgisdóttir et al., 2023). Other long-term consequences reported in the literature include self-harm and suicidal ideations (Weinstock et al., 2021). Bereavement during childhood significantly increases the risk of deliberate self-harm hospitalisations, and parentally bereaved teenagers have a higher risk of self-injury 6-9 years post-loss (Burrell et al., 2021; Hoffmann et al., 2018).

Aside from prolonged grief and self-harm ideations, another reported consequence is education performance. Children who had experienced parental death by external causes had a significantly reduced hazard ratio (HR) of completing all educational levels compared to children who did not have such experiences, most evident was completion of high school (HR 0.68, 95% CI 0.65–0.71) and University or College education (HR 0.75, 95% CI 0.70–0.80) (Burrell et al., 2020; Burrell et al., 2021).

Cancer-bereaved children had a significantly increased risk of first prescription of psychotropic medication (rate ratio, RR 1.22, 95% confidence interval, CI 1.10–1.34 for males; RR 1.18, 95% CI 1.09–1.28 for females) (Høeg et al., 2023). Associations were strongest if the parent had the same sex as the child and if the parent died within one year of diagnosis. The risk was highest during the first six months after the loss (RR 2.35, 95% confidence interval, CI 1.48–3.73 for males; RR 1.81, 95% CI 1.17–2.80 for females) (Høeg et al., 2023). Children who lose a parent to cancer, particularly in cases when the disease progressed quickly, may need extra psychological support, especially during the first six months after the death (Høeg et al., 2023).

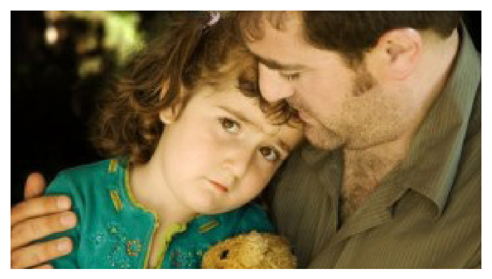
With this increased understanding of the immediate, medium-term, and long-term effects on children and young people of the loss of a family member, it is critical that the needs of bereaved Irish children are identified and addressed as early as possible.

Support and Services for Bereaved Children

When all the aforementioned factors are considered, both those that influence bereavement, and the potential outcomes of bereavement, successful support services for bereaved children are essential to help children to cope with grief and loss. However, there are still shortcomings in support services. The level and type of support available varies widely across states and countries (Wray et al. 2022) Frequently, educators report that they lack training on grief counseling, and nurses feel inadequately prepared to assist families and children in the acute phases of bereavement (Marcussen et al. 2019, Morell-Velasco et al. 2020, Schonfeld and Demaria, 2018). Timing of delivery of support is an important factor – strategies to support children through bereavement should be initiated closer to their loss experience and should include people who were well known to the child before the loss, such as family members or even the school environment (Farella Guzzo and Gobbi 2021, Hoffmann et al. 2018, Wray et al. 2022, Ross et al. 2021).

A consensus statement of childhood bereavement experts recommends that support should also be offered on an ongoing basis, with built-in flexibility to meet individual needs (Sandler et al. 2021). Some examples of support services include group sessions, which were most-frequently identified, individual and family therapy, telephone support, conferences, and onward referral programs (Bergman et al. 2017, Ridley and Frache 2020). These interventions focus on sharing and expressing loss, grief education, maintaining relationships and memories, learning coping skills and methods of self-reflection (Bergman et al. 2017, Ridley and Frache 2020). An example of a support strategy includes the Good Grief Program, a 3-day camp-based program which showed significant improvement in coping abilities, reducing unmet needs of overall support, and assisted in future planning (Patterson et al. 2021). Another service is called the Family Bereavement Program, which involves training on cognitive and behavioural skills, and was found to have a significant effect on reducing the prevalence of major depression at the 15-year follow-up (odds ratio 1⁄4 0.332, p < .01) (Sandler et al. 2023). A few other examples of different programs include the Coalition to Support Grieving Students, Resilience Songwriting Program, Let's Talk Suicide, Divorced Family-Focused Care Model, Lionheart Camp for Kids, CBT Grief-Help and The "Let's Talk About It" workshop (Griffiths et al. 2022, Marcussen et al. 2019, Ridley and Frache 2020, Schonfeld and Demaria 2018, Boelen et al. 2021, Myers-Coffman et al. 2019, Krysinska et al. 2023, Linder et al. 2022, Martínez-Caballero et al. 2023, Ridley et al. 2021). All of these services utilise evidence-based guidelines, policies, and standards to support children and adolescents through bereavement.

The timing of delivery of support is important – strategies to support bereaved children should be initiated closer to their loss experience and should include people who were well known to the child before the loss.



This Photo by Unknown Author is licensed under CC BY-SA-NC

A recently published systematic review highlighted the significant impact of Cognitive behavioral therapy (CBT) when used in the treatment of prolonged grief symptoms in the pediatric population. A sample of 20 studies were included in the review and the results showed significant improvements in prolonged grief symptoms and global functioning following CBT. No significant age, gender, or ethnicity differences were reported in most studies with significant effect sizes found for primary and most secondary outcomes. CBT should be considered for the treatment of prolonged grief symptoms in children and young people.

Conclusion

The prevalence of childhood bereavement is evolving and over the last five years, an increased number of children have suffered the loss of family members and loved ones, due to the COVID-19 pandemic. There is a growing body of research on children's understanding and reactions to death, dying, and bereavement. Previous research has highlighted psychological, physical, and social implications. A small number of grieving children can experience more complex symptoms of grief including depression and anxiety, negative emotions, educational difficulties and potentially even aggressive behaviour and self-harm. Over time, these reactions to bereavement can have lasting consequences. Long-term, some children and young people demonstrate major depressive disorders, self-harm ideations, difficulty progressing in secondary and further education. The way children react to bereavement, and the associated long-term outcomes, can be influenced by external and internal factors. Internal factors include race and ethnicity, socioeconomic status, and developmental stages. External factors include the relationships they have with peers and siblings along with other family members, their overall emotional responses, and the stability of their environment, including both family and community. Nonetheless, most children and young people can cope and manage their well if given information, support, and reassurance early from a trusted adult in their lives.

Appendix C

Alignment with Irish Childhood Bereavement Care Pyramid

Standard 1 Child and Young Person

In determining an individual child's needs, consideration should be given to the developmental stage, family context (availability of family support), and timing of any intervention.

All bereaved children may exhibit level 1 needs and require explanation and reassurance from a trusted person in their lives who understands children's reaction to loss and is aware of how to access organised bereavement services.

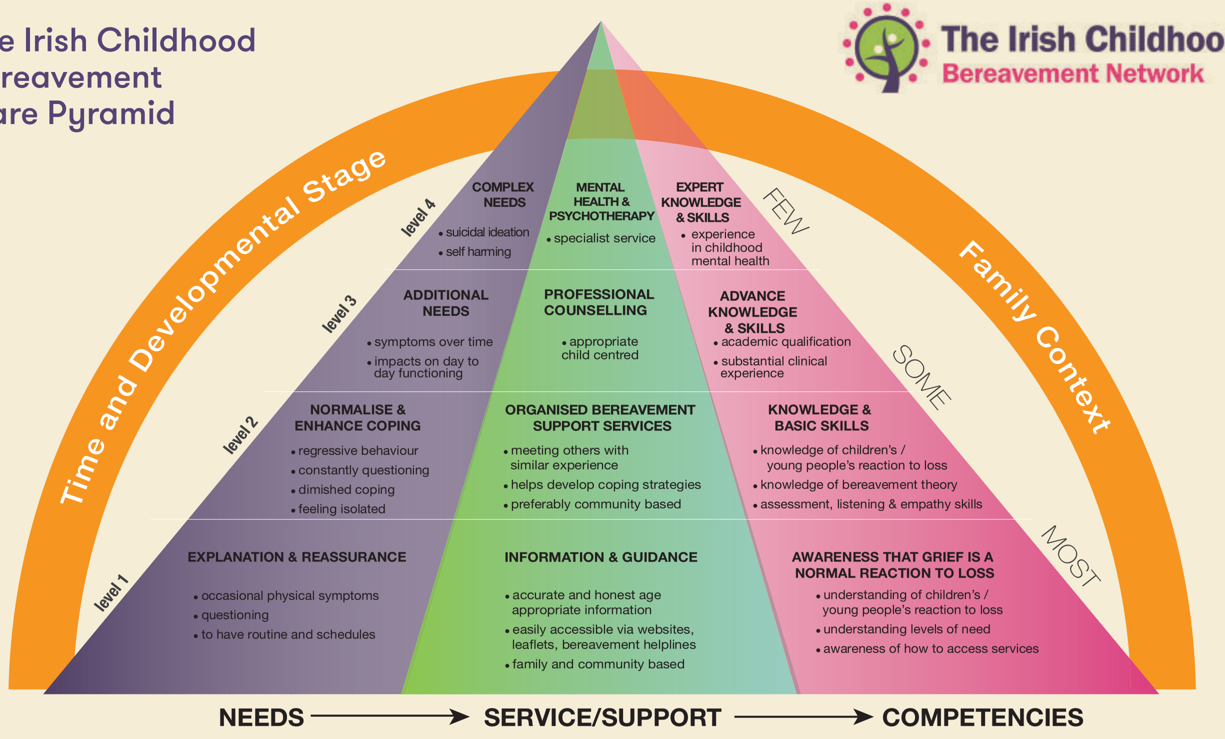
Some may need extra support at level 2 in parallel from the supports by family and community. The need for intervention at levels 3 and 4 is only required in a smaller cohort but essential if indicated.

Standard 2 Family

The family context and ability to provide level 1 care is crucial in supporting a bereaved child or young person. If it is determined that family support is limited or hindered in any way, this may elevate the needs of the child or young person from level 1 to level 2, and external services will be needed to optimise bereavement care.

Even if external support is needed, all children will benefit from explanation and reassurance from a trusted person in their lives as well.

The Irish Childhood Bereavement Care Pyramid



The Irish Childhood Bereavement Network

Standard 3 Local Community

Many children's needs can be fully met by their family with back up from within the community via information and guidance at level 1 and where needed via organised bereavement support services at level 2.

Most children and young people spend a lot of time in school and therefore, having access to level 1 support within their school from teachers and others is paramount. For those providing support at a community level, it is important to have basic knowledge and skills including knowledge of bereavement theory, awareness of children and young peoples' reactions to loss, and skills in assessment, listening, and empathy.

Standard 4 Service Providers

Service providers can operate at all levels of the Pyramid. Supports and services can range from information and guidance, organised bereavement support services, professional counselling, and mental health and psychotherapy. They are especially essential in supporting those 'few' children and young people with level 3 or 4 needs, where advanced and expert knowledge and skills are required.

Standard 5 National

The ICBN Pyramid and Standards set out the overall support structures required to ensure the needs of all children and young people are met; that services and supports are in place at individual, family, community, regional, and national level; and that training and education is readily available to people providing support at all levels.

The ICBN Pyramid and these Standards provide a clear evidence base for the adoption of childhood bereavement policy and strategy at a national level.

Appendix D

Consideration of AGREE Reporting Checklist 2016 in Standards Update

The AGREE Reporting Checklist (Brouwers et al., 2016)[1] is a widely used standard for assessing the methodological quality of practice guidelines. Although the ICBN Standards are not clinical practice guidelines, every effort was made to ensure the update was conducted in a rigorous and transparent manner. The table below outlines where and how the Standards update aligned with items on the AGREE Reporting Checklist 2016.

CHECKLIST ITEM AND DESCRIPTION	REPORTING CRITERIA	COMMENT FROM RESEARCH TEAM
DOMAIN 1: SCOPE AND PURPOSE		
1. OBJECTIVES *Report the overall objective(s) of the guideline. The expected health benefits from the guideline are to be specific to the clinical problem or health topic.*	☑ Health intent(s) (i.e., prevention, screening, diagnosis, treatment, etc.)	Reported in the introductory section
	☑ Expected benefit(s) or outcome(s)	Reported in the introduction section and throughout the document
	☑ Target(s) (e.g., patient population, society)	Reported in the introductory section
2. QUESTIONS *Report the health question(s) covered by the guideline, particularly for the key recommendations.*	☑ Target population	The target population is clearly reported
	☐ Intervention(s) or exposure(s)	N/A
	☐ Comparisons (if appropriate)	N/A
	☑ Outcome(s)	Practical examples of expected outcomes are reported throughout the document
	☑ Healthcare setting or context	The Standards apply to multiple settings ranging from a family setting up to national policymaking

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[1] *For more information about the AGREE Reporting Checklist, please visit the AGREE Enterprise website at www.agreetrust.org.*

3. POPULATION *Describe the population (i.e., patients, public, etc.) to whom the guideline is meant to apply.*	☑ Target population, sex, and age	The target population is clearly reported
	☑ Clinical condition (if relevant)	It is clearly reported that the Standards apply to all bereaved children and young people ranging from those who require minimal support to those who require advanced support
	☑ Severity / stage of disease (if relevant)	It is clearly reported that the Standards apply to all bereaved children and young people ranging from those who require minimal support to those who require advanced support
	☐ Comorbidities (if relevant)	N/A
	☑ Excluded populations (if relevant)	It is clearly reported that the Standards do not pertain to adult populations
DOMAIN 2: STAKEHOLDER INVOLVEMENT		
4. GROUP MEMBERSHIP *Report all individuals who were involved in the development process. This may include members of the steering group, the research team involved in selecting and reviewing/rating the evidence and individuals involved in formulating the final recommendations.*	☑ Name of participant	This is provided in the Acknowledgements section of the document.
	☑ Discipline content expertise (e.g., neurosurgeon, methodologist)	This is provided in the Acknowledgements section of the document.
	☑ Institution (e.g., St. Peter's hospital)	This is provided in the Acknowledgements section of the document.
	☑ Geographical location (e.g., Seattle, WA)	This is provided in the Acknowledgements section of the document.
	☑ A description of the member's role in the guideline development group	This is provided in the Acknowledgements section of the document.

5. TARGET POPULATION PREFERENCES AND VIEWS *Report how the views and preferences of the target population were sought/considered and what the resulting outcomes were.*	☑ Statement of type of strategy used to capture patients'/publics' views and preferences (e.g., participation in the guideline development group, literature review of values and preferences)	An extensive literature review was conducted to gather insights into the experiences and perspectives of bereaved children and young people. Furthermore, members of the stakeholder and advisory committee have extensive experience working with bereaved children and young people and some members were representatives of public bodies.
	☑ Methods by which preferences and views were sought (e.g., evidence from literature, surveys, focus groups)	- Evidence from the literature - A national survey of childhood bereavement services - Consultation meetings with a stakeholder and advisory committee
	☑ Outcomes/information gathered on patient/public information	Information gathered was used to update and revise the Standards
	☑ How the information gathered was used to inform the guideline development process and/or formation of the recommendations	Recommendations were reviewed in light of the findings of the literature review and revised as needed to reflect current evidence. Furthermore, findings from a national survey of childhood bereavement services were integrated into the report where relevant. Feeback and insights gathered during the consultation meetings were used to consolidate some information and enhance the usability of the Standards for stakeholders.
6. TARGET USERS *Report the target (or intended) users of the guideline.*	☑ The intended guideline audience (e.g. specialists, family physicians, patients, clinical or institutional leaders / administrators)	Reported in the introductory section
	☑ How the guideline may be used by its target audience (e.g., to inform clinical decisions, to inform policy, to inform standards of care)	Reported in the introductory section
DOMAIN 3: RIGOUR OF DEVELOPMENT		
7. SEARCH METHODS *Report details of the strategy used to search for evidence*	☑ Named electronic database(s) or evidence source(s) where the search was performed (e.g., MEDLINE)	PubMed and Cochrane library
	☑ Time periods searched	2018 to 2023 (building on the previous edition of the Standards)
	☑ Search terms used	Noted in Appendix B of this document (literature review report)
	☑ Full search strategy included (in appendix)	PRISMA chart and search tables reported in Appendix B.

8. EVIDENCE SELECTION CRITERIA *Report the criteria used to select (i.e., include and exclude) the evidence. Provide rationale, where appropriate.*	☑ Target population (patient, public, etc.) characteristics	PICOC framework and search methods reported in Appendix B.
	☑ Study design	PICOC framework and search methods reported in Appendix B.
	☐ Comparisons (if relevant)	N/A
	☑ Outcomes	PICOC framework and search methods reported in Appendix B.
	☑ Language (if relevant)	PICOC framework and search methods reported in Appendix B.
	☑ Context (if relevant)	PICOC framework and search methods reported in Appendix B.
9. STRENGHTS AND LIMITATIONS OF THE EVIDENCE *Describe the strengths and limitations of the evidence. Consider from the perspective of the individual studies and the body of evidence aggregated across all the studies. Tools exist that can facilitate the reporting of this concept.*	☐ Study design(s) included in body of evidence	N/A – a narrative analysis was conducted, and the focus was on emerging themes related to childhood bereavement. Hence, study design was not considered in the body of evidence.
	☐ Study methodology limitations (sampling, blinding, allocation concealment, analytical methods)	N/A – a narrative analysis was conducted, and the focus was on emerging themes related to childhood bereavement. Therefore, quality appraisal of individual studies was not conducted.
	☐ Appropriateness/relevance of primary and secondary outcomes considered	N/A – a narrative analysis was conducted, and the focus was on emerging themes related to childhood bereavement. Therefore, quality appraisal of individual studies was not conducted.
	☐ Consistency of results across studies	N/A – a narrative analysis was conducted, and the focus was on emerging themes related to childhood bereavement. Therefore, quality appraisal of individual studies was not conducted.
	☐ Direction of results across studies	N/A – a narrative analysis was conducted, and the focus was on emerging themes related to childhood bereavement. Therefore, quality appraisal of individual studies was not conducted.
	☐ Magnitude of benefit vs magnitude of harm	N/A – no comparator standard of practice treatments or interventions are available. The Standards seek to provide an overarching framework for the design and implementation of bereavement support services for children and young people.
	☑ Applicability to practice context	Practical examples of application in varied practice contexts are reported throughout the document.

10. FORMULATION OF RECOMMENDATIONS *Describe the methods used to formulate the recommendations and how final decisions were reached. Specify any areas of disagreement and the methods used to resolve them.*	☑ Recommendation development process (e.g., steps used in modified Delphi technique, voting procedures that were considered)	Utilisation of a modified Delphi technique or other formal voting procedures was not deemed appropriate in updating these Standards. It was agreed that an extensive review of the literature and consultation meetings with a stakeholder and advisory committee would be sufficient to update the Standards.
	☑ Outcomes of the recommendation development process (e.g., extent to which consensus was reached using modified Delphi technique, outcome of voting procedures)	Members of the stakeholder and advisory group were invited to review the edited Standards and provide comments that were then integrated into the updated Standards. During the consultation meetings, consensus was achieved in terms of agreed revisions and suggested ways of enhancing the usability of the Standards.
	☑ How the process influenced the recommendations (e.g., results of Delphi technique influence final recommendation, alignment with recommendations and the final vote)	All comments, insights, and feedback were incorporated into the revised Standards. Recommendations did not change significantly from the prior first edition.
11. CONSIDERATION OF BENEFITS AND HARMS *Report the health benefits, side effects, and risks that were considered when formulating the recommendations.*	☐ Supporting data and report of benefits	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations
	☐ Supporting data and report of harms/side effects/risks	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations
	☐ Reporting of the balance/ trade-off between benefits and harms/side effects/risks	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations
	☐ Recommendations reflect considerations of both benefits and harms/side effects/risks	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations

12. LINK BETWEEN RECOMMENDATIONS AND EVIDENCE *Describe the explicit link between the recommendations and the evidence on which they are based.*	☑ How the guideline development group linked and used the evidence to inform recommendations	Recommendations were reviewed in light of the findings of the literature review and revised as needed to reflect current evidence. Furthermore, findings from a national survey of childhood bereavement services were integrated into the report. Feeback and insights gathered during the consultation meetings were used to consolidate some information and enhance the usability of the Standards for stakeholders.
	☑ Link between each recommendation and key evidence (text description and/or reference list)	An extensive reference list is included in the revised document and a detailed literature review report is included in Appendix B.
	☑ Link between recommendations and evidence summaries and/or evidence tables in the results section of the guideline	An extensive reference list is included in the revised document and a detailed literature review report is included in Appendix B.
13. EXTERNAL REVIEW *Report the methodology used to conduct the external review.*	☑ Purpose and intent of the external review (e.g., to improve quality, gather feedback on draft recommendations, assess applicability and feasibility, disseminate evidence)	Consultations with external stakeholders and advisors was conducted to improve quality of the document, gather feedback on revisions, and enhance the usability of the Standards for all stakeholders.
	☑ Methods taken to undertake the external review (e.g., rating scale, open-ended questions)	Stakeholders and advisors were provided with an opportunity to review the document.
	☑ Description of the external reviewers (e.g., number, type of reviewers, affiliations)	A description of external reviewers is provided in the acknowledgement section of the report.
	☑ Outcomes/information gathered from the external review (e.g., summary of key findings)	Consultation meetings were video recorded and all comments / feedback on the draft revised document were saved in a shared drive.
	☑ How the information gathered was used to inform the guideline development process and/or formation of the recommendations (e.g., guideline panel considered results of review in forming final recommendations)	All comments, insights, and feedback were incorporated into the revised Standards. Recommendations did not change significantly from the prior first edition.

14. UPDATING PROCEDURE *Describe the procedure for updating the guideline.*	☑ A statement that the guideline will be updated	This is reported in the introduction section.
	☑ Explicit time interval or explicit criteria to guide decisions about when an update will occur	This is reported in the introduction section.
	☑ Methodology for the updating procedure	This is reported in the introduction section.
DOMAIN 4: CLARITY OF PRESENTATION		
15. SPECIFIC AND UNAMBIGUOUS RECOMMENDATIONS *Describe which options are appropriate in which situations and in which population groups, as informed by the body of evidence.*	☐ A statement of the recommended action	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations. However, criteria to measure whether a Standard has been met are provided throughout the document.
	☐ Intent or purpose of the recommended action (e.g., to improve quality of life, to decrease side effects)	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations. However, criteria to measure whether a Standard has been met are provided throughout the document.
	☐ Relevant population (e.g., patients, public)	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations. However, criteria to measure whether a Standard has been met are provided throughout the document.
	☐ Caveats or qualifying statements, if relevant (e.g., patients or conditions for whom the recommendations would not apply)	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations. However, criteria to measure whether a Standard has been met are provided throughout the document.
	☐ If there is uncertainty about the best care option(s), the uncertainty should be stated in the guideline	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations. However, criteria to measure whether a Standard has been met are provided throughout the document.

16. MANAGEMENT OPTIONS *Describe the different options for managing the condition or health issue.*	☐ Description of management options	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations. However, criteria to measure whether a Standard has been met are provided throughout the document.
	☐ Population or clinical situation most appropriate to each option	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations. However, criteria to measure whether a Standard has been met are provided throughout the document.
17. IDENTIFIABLE KEY RECOMMENDATIONS *Present the key recommendations so that they are easy to identify.*	☑ Recommendations in a summarised box, typed in bold, underlined, or presented as flow charts or algorithms	The Standards are summarised in coloured font and using icons throughout the document.
	☑ Specific recommendations grouped together in one section	The Standards pertain to give different groups and levels of bereavement support.
DOMAIN 5: APPLICABILITY		
18. FACILITATORS AND BARRIERS TO APPLICATION *Describe the facilitators and barriers to the guideline's application.*	☐ Types of facilitators and barriers that were considered	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations.
	☐ Methods by which information regarding the facilitators and barriers to implementing recommendations were sought (e.g., feedback from key stakeholders, pilot testing of guidelines before widespread implementation)	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations.
	☐ Information/description of the types of facilitators and barriers that emerged from the inquiry (e.g., practitioners have the skills to deliver the recommended care, sufficient equipment is not available to ensure all eligible members of the population receive mammography)	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations.
	☐ How the information influenced the guideline development process and/or formation of the recommendations	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations.

19. IMPLEMENTATION ADVICE / TOOLS *Provide advice and/or tools on how the recommendations can be applied in practice.*	☑ Additional materials to support the implementation of the guideline in practice. For example:	Links to further information and resources are provided. Handouts are provided in Appendix A, Appendix C, and Appendix E.
20. RESOURCE IMPLICATIONS *Describe any potential resource implications of applying the recommendations*	☐ Types of cost information that were considered (e.g., economic evaluations, drug acquisition costs)	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations.
	☐ Methods by which the cost information was sought (e.g., a health economist was part of the guideline development panel, use of health technology assessments for specific drugs, etc.)	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations.
	☐ Information/description of the cost information that emerged from the inquiry (e.g., specific drug acquisition costs per treatment course)	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations.
	☐ How the information gathered was used to inform the guideline development process and/or formation of the recommendations	N/A – the Standards are not clinical guidelines and do not offer clinical practice recommendations.

21. MONITORING / AUDITING CRITERIA *Provide monitoring and/or auditing criteria to measure the application of guideline recommendations.*	☑ Criteria to assess guideline implementation or adherence to recommendations	Practical examples of achievement of each Standard and criteria to demonstrate the Standard has been met were provided.
	☐ Criteria for assessing impact of implementing the recommendations	N/A – given the far-reaching application of the Standards as an overarching framework for bereavement support services, it was not possible to provide specific criteria to assess the impact of implementing each Standard. This would need to be determined by each bereavement support service organisation.
	☐ Advice on the frequency and interval of measurement	N/A – given the far-reaching application of the Standards as an overarching framework for bereavement support services, it was not possible to provide specific advice on the frequency or interval of measurement. This would need to be determined by each bereavement support service organisation.
	☐ Operational definitions of how the criteria should be measured	N/A – given the far-reaching application of the Standards as an overarching framework for bereavement support services, it was not possible to provide operational definitions on how the criteria should be measured. This would need to be determined by each bereavement support service organisation.
DOMAIN 6: EDITORIAL INDEPENDENCE		
22. FUNDING BODY *Report the funding body's influence on the content of the guideline.*	☑ The name of the funding body or source of funding (or explicit statement of no funding)	Included in the beginning of the document.
	☑ A statement that the funding body did not influence the content of the guideline	Included in the beginning of the document.
23. COMPETING INTERESTS *Provide an explicit statement that all group members have declared whether they have any competing interests.*	☑ Types of competing interests considered	Included in the beginning of the document.
	☑ Methods by which potential competing interests were sought	Included in the beginning of the document.
	☑ A description of the competing interests	Included in the beginning of the document.
	☑ How the competing interests influenced the guideline process and development of recommendations	Included in the beginning of the document.

Appendix E

Self-Assessment Checklist for Bereavement Services

	Criteria met	Criteria outstanding	Action required. By whom?
Checklist for registered charity organisations:			
All necessary governance procedures are in place to guarantee a transparent service which is run to the highest standards (as set out in the Charities Act 2009 and any future amendments or updates to charity regulation legislation).			
Policies and procedures to ensure that records are maintained in a confidential manner in accordance with the Data Protection Act (2018) and the Freedom of Information Act 2014.			
Adherence to the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016.			
Adherence to Children First Act 2015 and National Child Protection Guidelines.			
Adherence to relevant national regulatory requirements, including those outlined above and all other requirements relevant to your organisation.			
Checklist for all organisations (including registered charity organisations):			
Clear, accurate and up to date written information outlining the range of services and identifies the level(s) of specific need it can meet.			
Document clearly the model of care within your service.			
Knowledge of contemporary understanding of children's grief and appropriate interventions.			
Provision of information on children's bereavement through leaflets, useful links, websites, information on further reading materials.			

	Criteria met	Criteria outstanding	Action required. By whom?
Clearly identified referral pathways to all levels of bereavement support offered by a service provider and structure of referral if the provider finds that child's needs do not align with the services they provide.			
Written consent of parents or guardians for children to access services, and verbal assent from the child who is availing of support.			
Transparent assessment of the child's bereavement intervention needs to ensure that the service being offered is the most appropriate at that time and can be met by the service provider.			
Evaluation and feedback policies and procedures.			
An awareness of the limitations of confidentiality when working with children.			
A safe process of recruitment, selection, and probationary period for service personnel and volunteers.			
Training and support of all staff and volunteers to underpin the service level provided.			
Regular professional supervision, Continuous Professional Development, and self-care activities for all individuals involved in supporting bereaved children.			
Providing 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			
Adherence to relevant national regulatory requirements, including those outlined above and all other requirements relevant to your organisation.			

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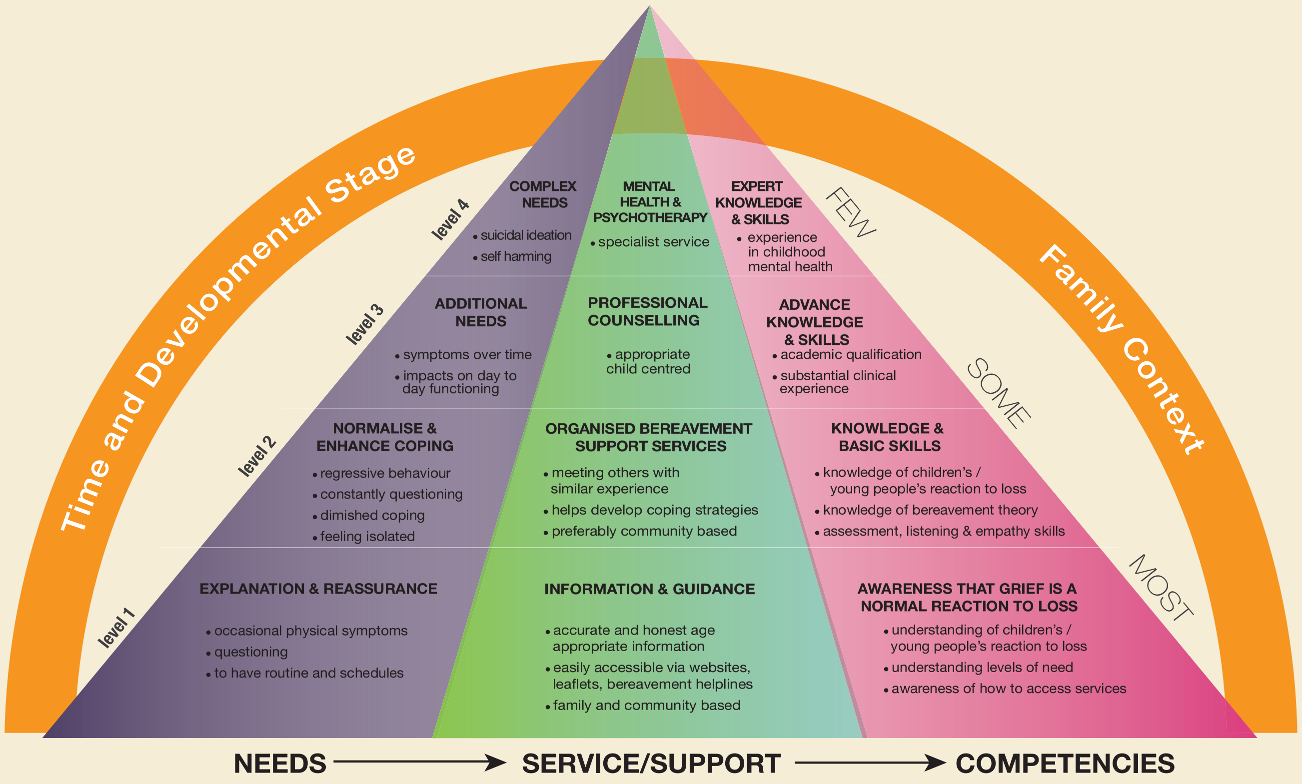
The Irish Childhood Bereavement Care Pyramid

The Irish Childhood Bereavement Network



Standard 1 Child and Young Person

In determining an individual child's needs, consideration should be given to the developmental stage, family context (availability of family support), and timing of any intervention.

All bereaved children may exhibit level 1 needs and require explanation and reassurance from a trusted person in their lives who understands children's reaction to loss and is aware of how to access organised bereavement services.

Some may need extra support at level 2 in parallel from the supports by family and community. The need for intervention at levels 3 and 4 is only required in a smaller cohort but essential if indicated.

Standard 2 Family

The family context and ability to provide level 1 care is crucial in supporting a bereaved child or young person. If it is determined that family support is limited or hindered in any way, this may elevate the needs of the child or young person from level 1 to level 2, and external services will be needed to optimise bereavement care.

Even if external support is needed, all children will benefit from explanation and reassurance from a trusted person in their lives as well.

Standard 3 Local Community

Many children's needs can be fully met by their family with back up from within the community via information and guidance at level 1 and where needed via organised bereavement support services at level 2.

Most children and young people spend a lot of time in school and therefore, having access to level 1 support within their school from teachers and others is paramount. For those providing support at a community level, it is important to have basic knowledge and skills including knowledge of bereavement theory, awareness of children and young peoples' reactions to loss, and skills in assessment, listening, and empathy.

Standard 4 Service Providers

Service providers can operate at all levels of the Pyramid. Supports and services can range from information and guidance, organised bereavement support services, professional counselling, and mental health and psychotherapy. They are especially essential in supporting those 'few' children and young people with level 3 or 4 needs, where advanced and expert knowledge and skills are required.

Standard 5 National

The ICBN Pyramid and Standards set out the overall support structures required to ensure the needs of all children and young people are met; that services and supports are in place at individual, family, community, regional, and national level; and that training and education is readily available to people providing support at all levels.

The ICBN Pyramid and these Standards provide a clear evidence base for the adoption of childhood bereavement policy and strategy at a national level.

Supporting those working with
grieving children and young people.

The Irish Childhood
Bereavement Network

The Irish Childhood Bereavement Network
Irish Hospice Foundation
32 Nassau Street
Dublin 2

Telephone: 01 679 3188

www.childhoodbereavement.ie