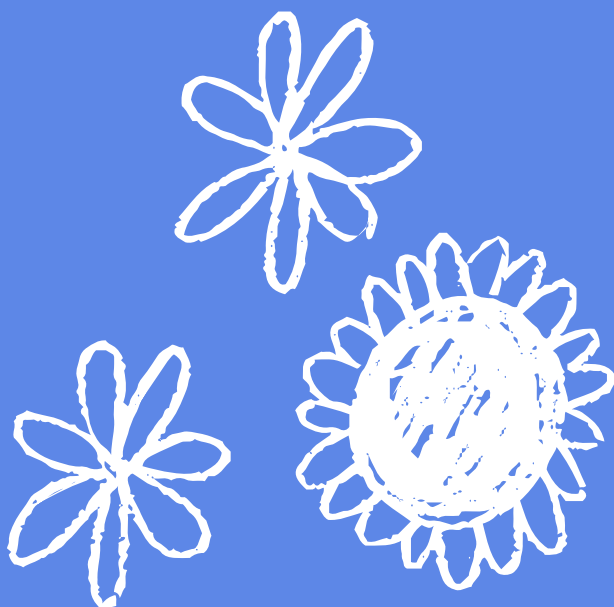


National Childhood Bereavement Project

Year One: Interim Report



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“ ”

For too long death has been treated as an 'adult' issue and young people have been sheltered from the conversation. But it affects us all, no matter our age.

“ ”

A Project Driven by Lived Experience



Glossary

Bereavement – When we talk about being ‘bereaved’, we are looking at the loss of any person who is significant to a child.

Childhood – We define ‘childhood’ as up to the age of 25, to allow us to capture the experiences of all infants, babies, children, young people and young adults and the long-lasting nature of grief.

Experts by Experience - Individuals with direct first-hand lived experience, past or present of childhood bereavement.

Family – When we refer to a ‘family’, we see this as determined by the young person, including anyone significant to them beyond their immediate birth families.

Supporting Adult – We see this as any adult with a role in supporting a young person, this goes beyond parents or carers to also include people like teachers and neighbours.

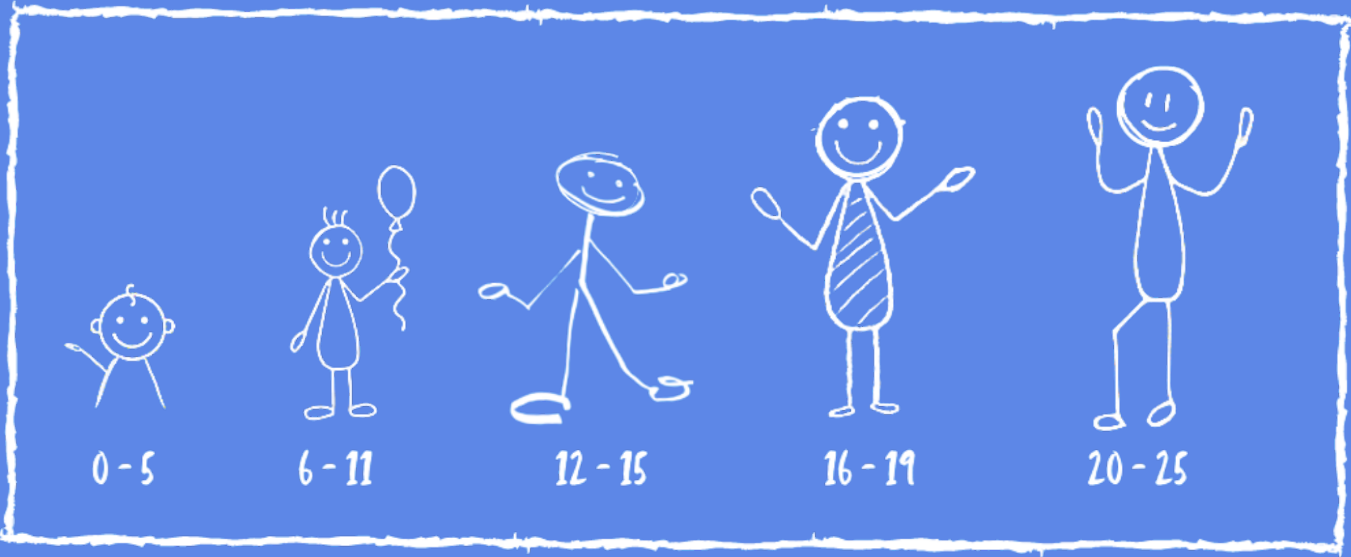
Get in touch:

If you would like to find out more about the project or to sign up to our newsletter you can get in touch with the project at:

bereavement@includem.co.uk

You can also find out more via our website:

includem.org/childhood-bereavement/



Introduction

The National Childhood Bereavement Project was established to realise the commitments made by Scottish Ministers to improve support for those who are bereaved during their childhood, as outlined in the Programme for Government 2016/17¹.

This interim report provides an update on progress made within the first twelve months of the project in relation to key deliverables and milestones set by the Scottish Government. This report also highlights emerging cross-cutting themes from the initial engagement with individuals and organisations supporting infants, children, young people, and young adults who have been bereaved. It has been created with and by those with direct lived experience of childhood bereavement, providing a platform for their views to be meaningfully heard.

The report will set out the draft plans for the final twelve months of the project which is set to conclude and report back with recommendations to the Scottish Government in March 2022. When the project was initially commissioned by the Scottish Government in early 2020, the world looked very different. The COVID-19 pandemic has brought issues of death, dying and bereavement into sharp focus. While the long-term consequences of the pandemic are still uncertain, we can already see the profound detrimental impact on the nations wellbeing².

Our children and young people have suffered major disruptions to their lives at an unprecetended rate. Research from Childhood Bereavement Network found that grieving infants, children, and young people have found the pandemic hard to cope with. 80% of widowed parents said their children had struggled with isolation and loneliness during the pandemic, and a further 79% reported that their children have had more of a problem with worry and anxiety³. Before the pandemic, at just eight years old 50% of children were found to have experienced the death of a close family member⁴.

Despite this evidence of widespread grief, the current picture of childhood bereavement in Scotland still underestimates its true prevalence and impact. Recent studies in this area do not factor children being bereaved beyond their immediate families, and the full extent of the COVID-19 pandemic has yet to be understood.

It is abundantly clear: no child is immune to experiencing the death of someone they love by virtue of their age. The effect of grief on a rapidly developing infant, child or adolescent brain can have a lasting impact which Scotland has a duty to mitigate and support. Now more than ever, we need a national conversation around death which centres the voices of those with lived experience to drive service innovation. It is, as such, the collective responsibility of the National Childhood Bereavement Project to outline what is needed to ensure support is available to all infants, babies, children, young people and young adults who experience a bereavement as and when they require it.

“It is abundantly clear: no child is immune to experiencing the death of someone they love by virtue of their age.”

¹ <https://www.gov.scot/publications/plan-scotland-scottish-governments-programme-scotland-2016-17/>

² https://nationalperformance.gov.scot/sites/default/files/documents/NPF_Impact_of_COVID-19_December_2020.pdf

³ <https://childhoodbereavementnetwork.wordpress.com/2020/11/19/pandemic-deepens-feelings-of-isolation-felt-by-grieving-families/>

⁴ <https://journals.sagepub.com/doi/full/10.1177/2632352420975043>

Background



Includem, a charity supporting children, young people, and families to transform their lives, was appointed as the National Childhood Bereavement coordinator in March 2020⁵.

Includem brings extensive third sector knowledge and a strong track record of working in partnership with charities, statutory service providers and local authorities to the role of the coordinator.

Our Mission:



To provide the support young people need to make positive changes in their lives, and inspire a more hopeful future for young people, their families and communities.



Our Vision:



A world where every young person is respected, valued, and has the opportunity to actively participate in all aspects of life and society.



What we do:



We work closely with children, young people, and their families, who are facing difficult challenges in their lives.

Our trust-based, inclusive model of support is centred on the needs of each young person. We help young people make positive life choices and empower them to transform their lives; creating better outcomes for young people, their families and communities.



The Scottish Government has outlined commitments to improving bereavement support in Cabinet meetings with children and young people⁶ and in Government strategy documents including the National Performance Framework and the Scottish Government's Mental Health Transition and Recovery plan⁷. Bereavement support also interacts with broader Scottish Government aspirations including the Getting It Right for Every Child (GIRFEC) approach for children to grow up Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, Included (SHANARRI).

Similarly, a wide range of professionals and individuals from across the Scottish policy landscape have dedicated their personal and professional lives to ensuring good bereavement support is fundamental to our society. This is evident through the development of vital resources such as the National Bereavement Charter for Scotland⁸ and the delivery of the Seasons for Growth programmes across Scotland.

The ethos behind the National Childhood Bereavement project is not a new phenomenon to Scotland. Our work seeks to join up the many discussions, consultations, engagements, and research that has come before the project and will come after its lifespan to create a country where all children and young people feel safe, nurtured and loved, complementing and building on existing efforts.



⁵ <https://includem.org/childhood-bereavement/>

⁶ <https://www.gov.scot/publications/third-annual-cabinet-meeting-with-children-and-young-people/>

⁷ <https://www.gov.scot/publications/mental-health-scotlands-transition-recovery/pages/16/>

⁸ <https://scottishcare.org/wp-content/uploads/2021/01/NESD1377-Bereavement-Charter-PRINT-V2.pdf>


Timeline of Events

MAR - MAY
2020



contract
awarded

SEP - NOV
2020



sector
engagement

MAY - SEP
2020



desk-based
research

NOV - DEC
2020

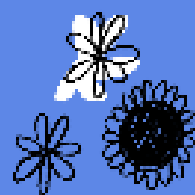
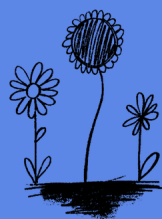


awareness
raising

JAN - MAR
2020



roundtable
discussions



Milestones & Key Deliverables

Milestone one

Provide project plan and timeline for the year with key deliverables and dates

Milestone two

Research the landscape for bereavement support for children and young people in Scotland and produce a vision of future support

Milestone three

Map service provision of bereavement support across Scotland including case studies of provision and support

Milestone four

Map workforce for bereavement and their training providers, outlining standards to be delivered against

Milestone five

Produce an analysis report and recommendations based on the analysis of service provision, outlining recommendations to fill the gaps

Milestone six

Provide a response to policy requests from Scottish Government, as and when required through-out the contract period

Milestone seven

Attendance at relevant networks and events as and when required

key deliverable one

Work with partners to develop an action plan, developing a vision for support for those children who have experienced bereavement

key deliverable two

Develop a framework of support

key deliverable three

Represent bereaved children and those supporting them at relevant policy networks and groups

key deliverable four

Carry out an audit of the current range of services available. Analysing the gaps in current provision through building on existing mapping work already carried out by the Childhood Bereavement network and working with partners to develop a plan to address the gaps

key deliverable five

Develop case studies of effective partnerships

key deliverable six

Map relevant workforce and training needs

key deliverable seven

Promote an understanding of bereavement across Scotland

key deliverable eight

Work with schools to develop the curriculum around bereavement

key deliverable nine

Develop a mechanism for involving bereaved children, young people and their families – through local services - in policy and practice development to allow them to share their views in order to inform practice

key deliverable ten

Actively seek views to influence policy positions, resources and planning tools

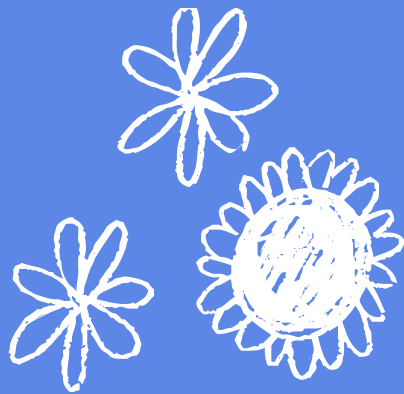
key deliverable eleven

Attend Childhood Bereavement Network meetings held throughout the year

key deliverable twelve

Provide quarterly reporting based on achievements against milestones, together with quarterly meetings with the lead contact within the Scottish Government Youth Justice team together with an end of contract report

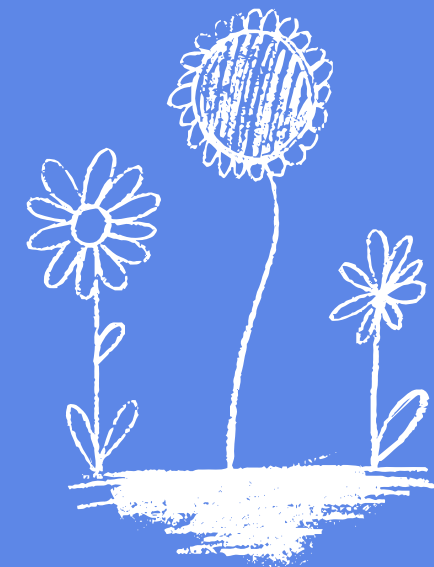
Phase One



The measures imposed to control the spread of the virus significantly hindered the beginning of the project as includem were unable to appoint a Project Lead and many relevant organisations, individuals, and support groups were either dealing with immediate changes to their own operations or ceased all activities in response to the pandemic.

To ensure no time was wasted, a team of includem staff completed a stage of desk-based research. The team included members of the senior management team and five experienced Project Workers based across a variety of local authority areas. Through interviews and surveys, the team gathered information about the type of support that is available, the criteria to access this, and the sustainability of the service. Where available, the research team also recorded relevant statistics of the number of children and young people who had received support. Additionally, we spoke with representatives from health, education, and social work, to gather information about the current approaches used to support children and young people who have experienced bereavement. Throughout this stage 105 key stakeholders were identified across Scotland who provided direct support to children and young people.

The culmination of this work produced a baseline of the current landscape of bereavement support for an incoming Project Lead to explore further. This included areas such as disparities in service provision in urban and rural areas, difficulties in accessing support, variation in available funding strands and the lack of strategic coordination bereavement support across Scotland.



Phase Two



The National Childhood Bereavement Project aimed to build meaningful participation opportunities for those who have a professional and/or personal experience of childhood bereavement in Scotland. To do this, **we have actively gathered the views of children and young people who have been bereaved, the supporting adults in their lives, and the individuals and organisations working to help them through their grief.**



Project Lead Appointed

Denisha Killoh is appointed
Project Lead September 2020



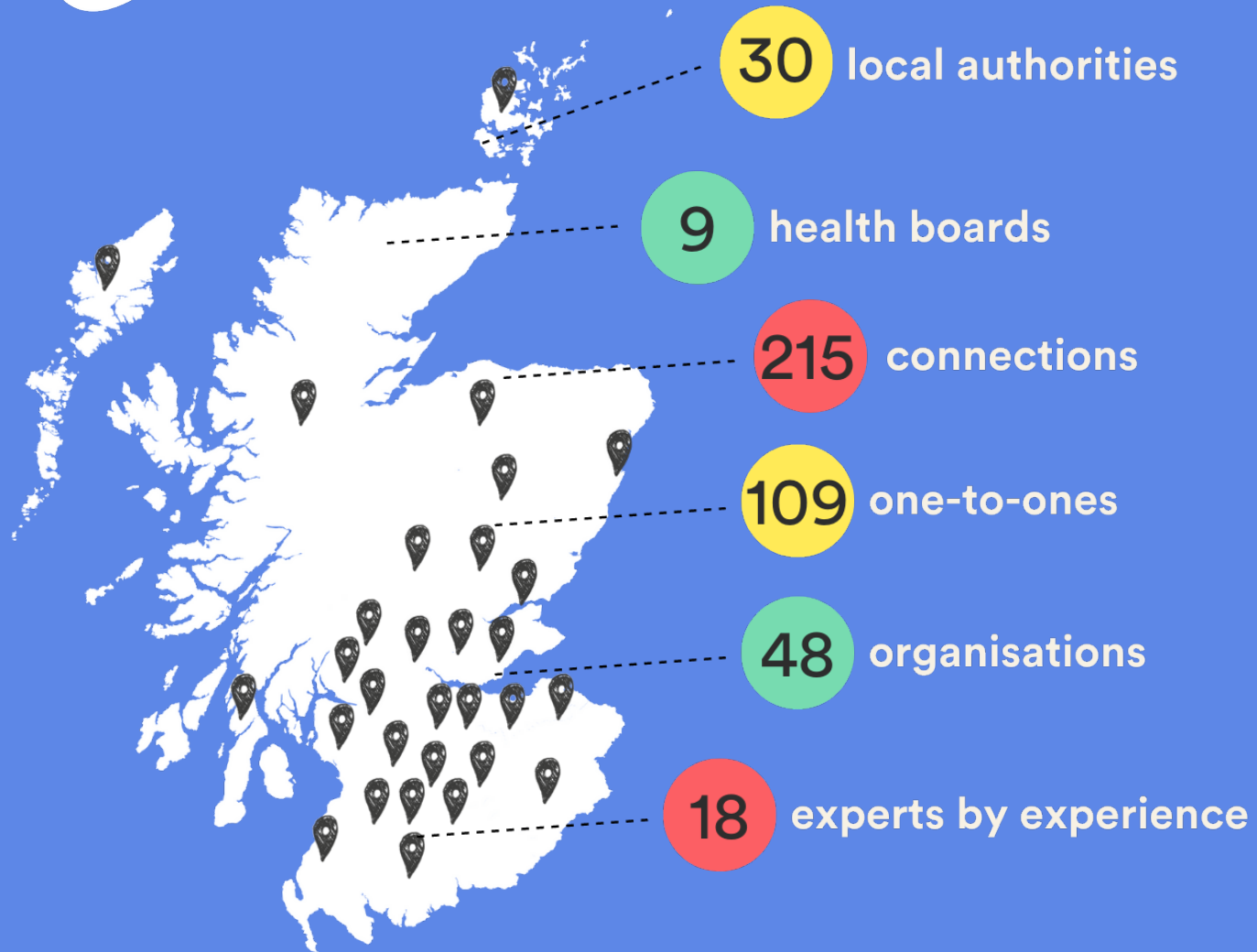
Accomplishments

- Secured a further 12 months of funding for the project
- Hosted four roundtable discussions across two themes gaining 30 attendees from across Scotland
- Signposted 6 people with lived experience and 5 individuals working with bereaved children and young people to bereavement support
- Attended 12 external online events, including a parliamentary hustings
- Regularly attending Bereavement Network Groups in 9 areas: Lothian, Lanarkshire, Fife, Tayside, Grampian, Forth Valley, Dumfries & Galloway, Highland and Glasgow

Awareness Raising

- Created a podcast episode on the impacts of childhood bereavement for Children's Grief Awareness Week
- Featured on BBC Reporting Scotland
- Established a project newsletter gaining 75 subscribers from across Scotland
- Produced a series of Instagram posts in partnership with [The Unheard Group](#) on young people's experience of loss
- Published an article in The Herald and contributed to a piece in the Holyrood Magazine
- Gained over 100,000 impressions across social media channels from project related posts

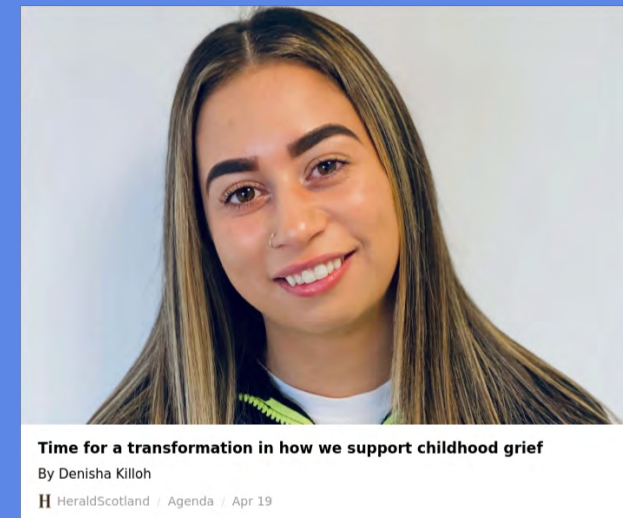
Our Engagement



We recognise that support for bereaved children and young people cannot be improved in a silo. Therefore, we have worked across several policy sectors to guarantee that each and every child grows up in an environment that enables them to flourish. This is including but not limited to, children and families, care, youth justice, health, and education.

The aim of our participation strategy is twofold: to bring together as many individuals working with bereaved children and young people as possible, whether that be directly or indirectly, to share their insights and reflections, and to develop a mechanism for involving those with lived experience of bereavement to shape our recommendations. **To realise these ambitions, we have been delivering two strands of work simultaneously.**

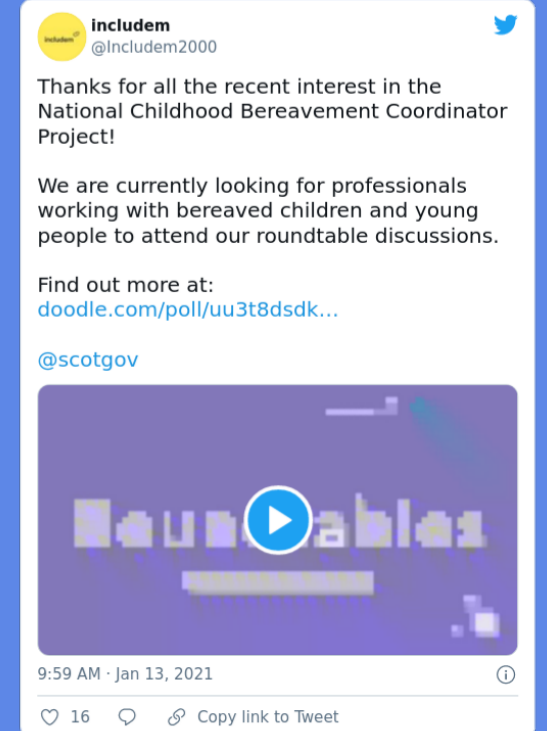
In The Media



Time for a transformation in how we support childhood grief
By Denisha Killoh
HeraldScotland | Agenda | Apr 19



A lesson in death: why bereavement should be on the school curriculum
Our death-denying society could be making it even harder for children to grieve
Holyrood Website | Nov 16, 2020



includem appointed National Childhood Bereavement Coordinator by Scottish Government

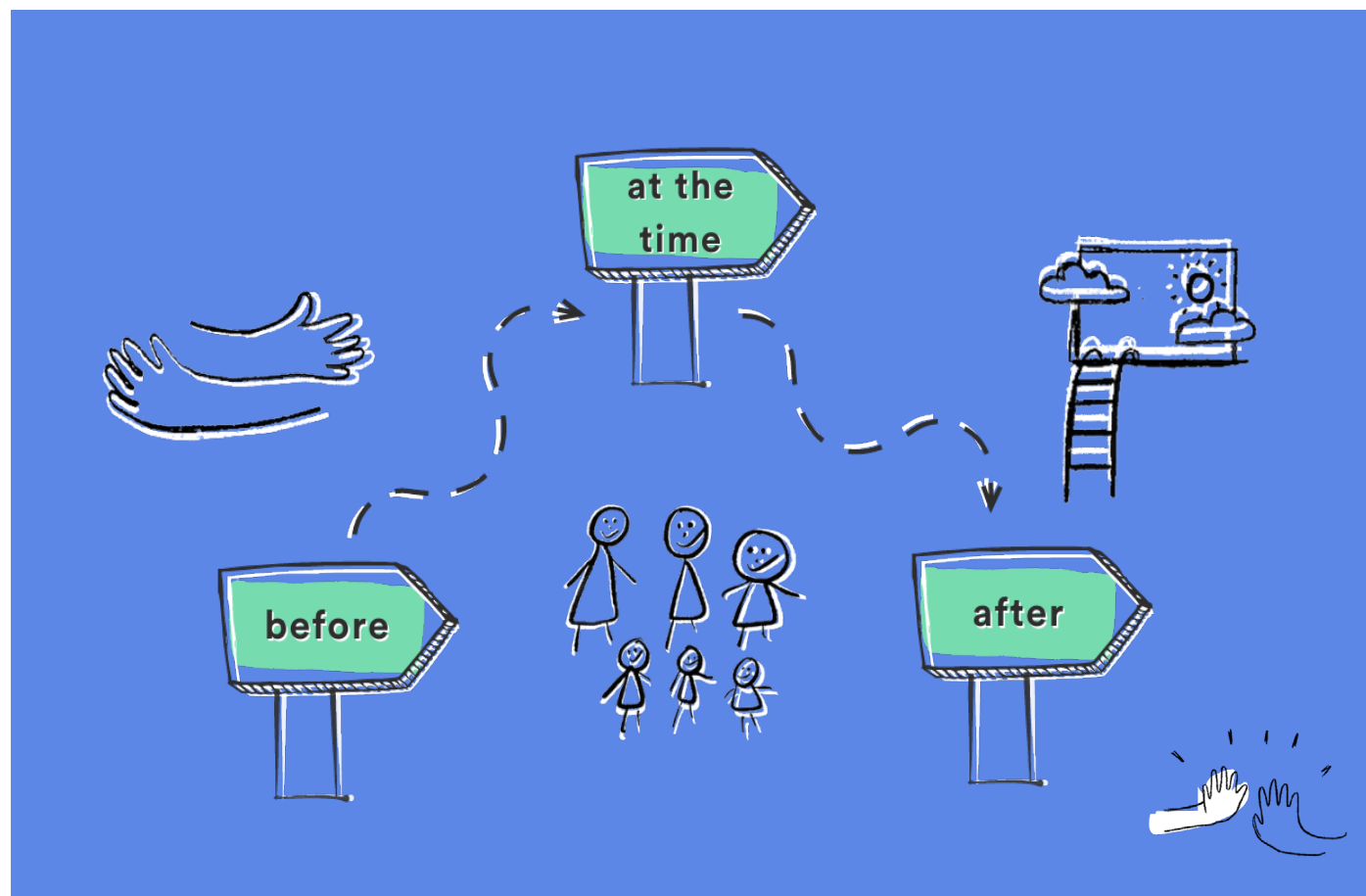
POSTED ON OCTOBER 23 2020 AT 08:00 Includem, Scotland's youth and family support charity, has been appointed by the Scottish Government as the National Childhood Bereavement Coordinator...

Includem

Timeline of Support

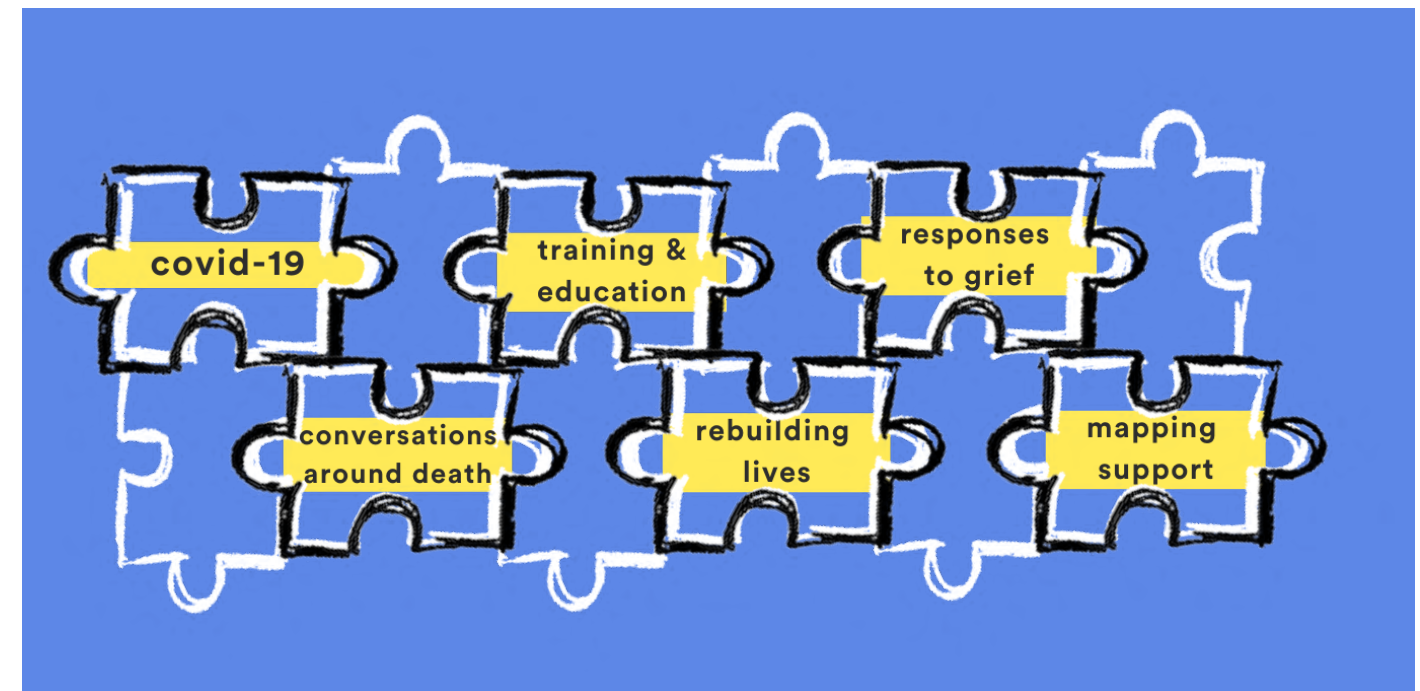
At the National Childhood Bereavement project, **we recognise that even the best outputs can be rendered useless if they are not accessible and relatable to their target audience.** With this in mind, we have **designed the project with the mechanisms in place to enable infants, children, and young people who have been bereaved to have a continuous influence in how it looks, acts, and feels.** This approach is in line with the ethical participation and co-production blueprint set out in The Promise⁹ and honours Article 12 of the UNCRC¹⁰, to ensure every child has the right to be heard in matters affecting them and to participate in the life of their family, community, and society.

Through continuous engagement with those with lived experience, we are working to produce a Timeline of Support to identify the disparities between the support people receive when they are bereaved, and the support people felt would have been beneficial to them. **To ensure the people we engage with feel heard and respected at all times, we have designed our participation approach with the aim of creating a safe environment to allow grief to be explored in a way that is meaningful to each individual. In supporting people to tell the story that matters to them, they have a space to remember the person who has died.**



Themes

From our desk-based research and our early conversations with individuals and organisations across Scotland, we identified cross-sector trends, common ground, and gaps in support. In partnership with those working with children and young people who have been bereaved, we developed six interconnected themes to be explored.



In order to gather the views of as many individuals from across the bereavement landscape as possible, we have hosted a series of broad, challenging, and inclusive conversations organised around our six identified themes. As of March 2021, the roundtables for the COVID-19 and Conversations Around Death themes have taken place. Both themes had two online sessions to explore a set of key questions. For each theme, there were one or two 'Key Collaborators' who are individuals with expertise in the field and have an existing relationship to the project appointed to jointly plan and facilitate the discussions.

Across these roundtables, there were 30 attendees from a range of backgrounds including universities, hospices, charities, educational psychology, local authorities, schools, youth centres, and health boards. 60% of the attendees had no previous engagement with the project, becoming aware of the roundtables through social media or mutual networks.

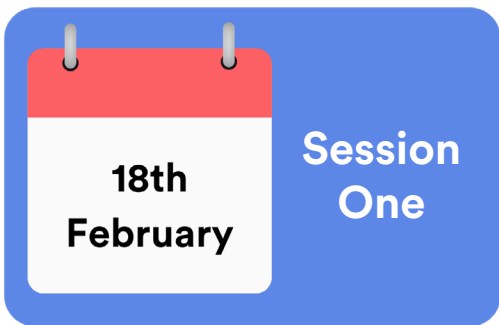


⁹ <https://www.carereview.scot/wp-content/uploads/2020/02/The-Promise.pdf>

¹⁰ <https://cypcs.org.uk/rights/uncrc/articles/article-12/>

Conversations Around Death

Exploring cultural and community influences on children and young people's experiences of bereavement

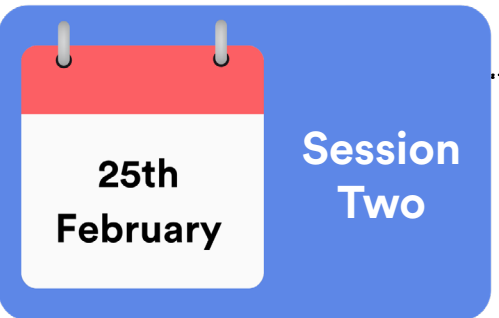


Session One

Session One

What are the ways that society/culture influence children and young people's experiences of bereavement in Scotland?

How can we equip communities to feel confident supporting young people who've been bereaved?



Session Two

Session Two

How do we empower young people who've been bereaved to ask for help and know what to do?

Have you got any examples of a place/community/initiative set up to support or improve the experiences of young people who've been bereaved? What have been the strengths and/or weaknesses?

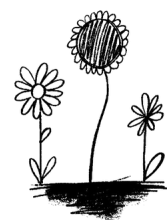
18 attendees

Key Collaborator



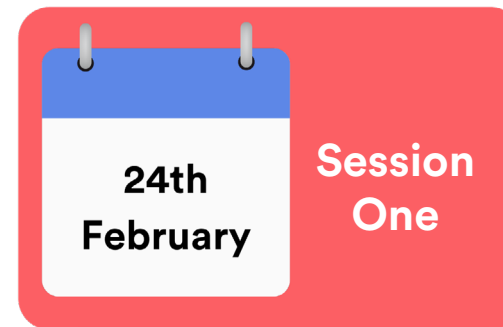
"Make sure we are all open, supported and willing to talk about death, dying and bereavement."

"Give young people safe space to talk about their feelings."



COVID-19

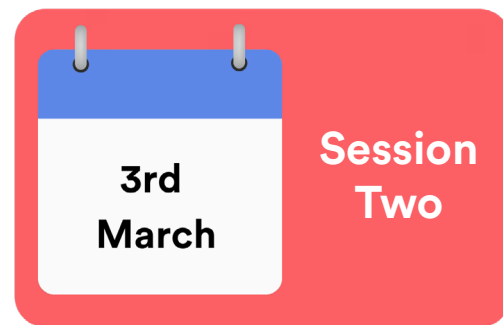
Exploring the impact on bereavement services for children and young people



Session One

Session One

What lessons have you learned from adapting your services?



Session Two

Session Two

What are the differences in experiencing grief before March 2020 and after March 2020?

What are the impacts of grief on individual and family systems during lockdown?

What are your experiences of how people are able to use bereavement services during the pandemic?

12 attendees

Key Collaborators



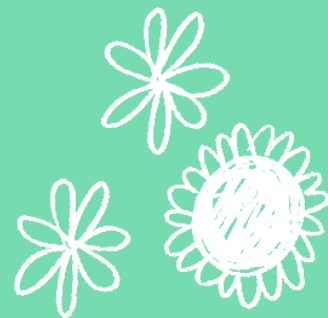
"Beyond the services themselves, a national conversation about death and dying so that there's greater grief literacy in wider society."

"Not seeing service interventions as the only way to support a young person."

The Impact of Pandemic Restrictions on Grieving



Year One Findings



The engagement carried out during year one of the project has allowed us to produce interim propositions to improve Scotland's bereavement landscape. These key findings are summarised under quotes from individuals the project has heard from, containing information gathered from the last 12 months of one-to-one meetings, roundtable discussions, events, and network groups.

“Everything in my armoury was taken away because of the shift to online.”

The coronavirus pandemic has forced our workforce to rapidly adapt to new ways of working. **Those who have continued to provide support throughout have told us the varying degrees of success their services have had.**

At the start of the pandemic practitioners generally assumed that the move to online support would be preferred by young people as they are considered a more technologically literate generation. Yet, this has not proved to be the case – with a consensus across the sector that many young people are feared to be ‘holding onto’ their grief until face-to-face services are able to resume. **There is a sense across service providers that it’s tougher to build authentic relationships online, especially when talking about traumatic experiences like bereavements, due to the inability to pick up on in-person cues that help you better respond to someone’s needs, like body language.** Additionally, certain online sessions with children now require a supporting adult to be present which can make it harder for young people to be honest about their feelings. These factors have been further exacerbated by lockdown restrictions preventing and/or limiting end of life rituals such as limited capacities at funerals and wakes.

Despite these challenges, many organisations have continued to provide high-quality support. Services have worked tirelessly to ensure volunteers and staff are trained up in both face-to-face and virtual delivery. Improvements in joined-up sector working have increased the number of networking events, encouraged greater sharing of resources, and improved the ability for those in remote communities to access support. Some charities have also had success in hosting virtual memorial days which has allowed families to come together from around the world over Zoom.

To learn from the hurdles services have overcome and to embed the positive work that has been achieved into our infrastructure, there is a consensus that taking a blended approach of face-to-face and virtual support post-pandemic is necessary to accommodate the widest range of needs.

Talking About Death

66 99

“No one talks about what happens when you die and how to cope afterwards.”

As a nation, we tend to shy away from talking about death in general. Conversations about death are avoided around children and young people, which can inadequately prepare them for the realities of bereavement.

In the ‘Conversations Around Death’ roundtable discussions, we explored the barriers some adults felt prevented them from talking about bereavement with children. We heard how some adults feel the need to protect young people from the implications of death - however, while it is not bad to shelter children from certain things, **avoiding conversations around death completely can have unintended consequences on a young person’s development.** Softening language to explain death to children can confuse their understanding of bereavement. Using phrases such as “they’ve went to sleep” can make children scared of going to bed in case they don’t wake up. Referring to the person who has died as being ‘lost’ through phrases like “we’ve lost them” or “I’m sorry you’ve lost them” indicates to children that they are something to be found.

Similarly, those directly supporting bereaved children and young people expressed that the reluctance from adults to talk openly about death with children can deepen the symptoms of grief because children internalise that it is not something to talk about - making them feel unable to cope when a significant person in their life dies.

“they’ve gone away”

“they’ve went to sleep”

Death, Dying, Grief & the School Environment

“You can have all the grades and education you want but when loss comes it instantly changes you – no amount of intelligence will prepare you for the journey of grief.”

Schools can act as a place of respite from home circumstances in a child’s life. Thus, it is important to ensure schools are properly equipped to support bereaved children and young people. For some of the individuals working with bereaved children and young people we have spoken to, this would ideally **require every school in Scotland to have a universal bereavement policy and procedure in place.** For others, they view updating the Curriculum for Excellence to incorporate elements of loss, grief, and bereavement into children’s education as an important step forward. Regardless of the form bereavement education may take, **it is crucial that the multicultural and diverse nature of Scottish citizens is taken into consideration during the development stage to ensure no one is left out of the conversation.**

We will explore this in more detail during our upcoming roundtable discussions themed around ‘Training & Education’. These discussions will gather teachers, educational psychologists, charity workers, training providers, and more to map the best course of action to incorporate death, dying and grief into a school environment.

We will also be working to carry forward the petition to Scottish Parliament on making bereavement education compulsory in schools by working in partnership with those involved¹¹. Any recommendations around education will be co-developed with existing training and education providers such as Seasons for Growth and Child Bereavement UK to ensure we are working collaboratively, not competitively.

“it is crucial that the multicultural and diverse nature of Scottish citizens is taken into consideration during the development stage to ensure no one is left out of the conversation.”

¹¹ <https://archive2021.parliament.scot/gettinginvolved/Petitions/bereavementeducation>

“We're all in the same storm but aren't all in the same boat”

Some young people may be ready to instantly talk about the person who has died, whereas others might need weeks, months or even years. Scotland cannot legislate for all forms of grief, nor should it try to. There is no ‘one size fits all’ when it comes to grief – it is an individual process that will affect everyone differently. What we should do, however, is put the foundations in place to create an environment where all infants, children and young people, both verbal and non-verbal feel safe and supported with their grief when they require it.

Through our Timeline of Support work, the young people who have engaged in the project thus far told us how we can begin to realise this vision.



“I wish I had help prior to my mum’s death to help come to terms with the fact she was going to die”

We have heard stories of young people struggling to adapt to life without the person who has died, feeling like everything was happening out of their control. When asked what could, in part, prepare them for being bereaved, young people told us that education on the grieving process in schools is key. They said that this would normalise the experience of being bereaved as it would be spoken about as a natural part of life. This would educate young people on how certain behaviours and feelings are symptoms of grief, making it easier to recognise and support someone going through a bereavement.

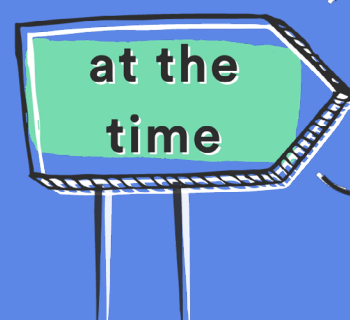
Similarly, pre-bereavement support for young person with someone close to them being diagnosed with an incurable illness is limited across the country. Some young people told us that they would benefit from support to deal with anticipatory grief such as peer support groups.

Grief as a Lifelong Condition



what did you feel changed?

what would have helped you?



“I want it to become normalised to speak about death and for less people to be uncomfortable around the topic so that it’s easier to speak about the person who has died”

Rebuilding your life after a bereavement is difficult at any age. But for young people growing up, the loss of a relationship that will never come to fruition can be particularly difficult to navigate. There is work to be done around normalising talking about dying, death and bereavement in daily life to make it easier for young people to feel that they have a safe space where they can lean on others to process their grief, regardless of how much time has passed or the age they were when they were bereaved.

Additionally, some young people discussed the burdens of having to take on things like debt and bills after a supporting adult in their lives has died.. With limited options in place to support young people in these situations, they can be pushed into precarity making an already difficult time harder. Young people told us that having access to grants and financial support after being bereaved would have helped them stay afloat.

“I wish there was an automatic referral to have someone to speak to after it rather than having to find it yourself”

When you are bereaved, it can feel as though every aspect of your life changes overnight.

If a young person experiences the death of their primary caregiver, they can find themselves having to rapidly uproot their home lives. This could mean having to move house, city or school as well as potentially learning to live with new people. All of these factors can make an already challenging situation more difficult, especially if you feel that there is no support around you. Similarly, young people told us that when they were bereaved it isolated them from others their age because they felt unable to speak to their friends about what they were going through.

At the time of a bereavement, young people expressed the need for improvements in signposting to available support. Others we spoke to called for an automatic referral to put them on the radar of services in case their grief manifests in crisis at a later date. There was also an emphasis on upskilling those already around the young person, such as their friends and teachers, to enable them to feel confident in offering the space to talk about their grief. They also suggested things like an increased provision of peer support groups to bring together other young people who have been bereaved, similar to the [Let's Talk About Loss](#) meetup groups.



it's changed who i am
entirely as a person

How has bereavement
affected you?

Type something...

i feel overwhelmed more often and
has made me appreciate the little
things in life more



other people my age to
speak to

What support do you wish
was available at a time you
lost someone ?

Type something...

someone explaining why i had so
many different emotions like anger
and guilt



Talked about how special
that person and didn't just
avoid the subject entirely

What do you wish people
had said to you?

Type something...

I know I don't understand but I
am here for you and I will listen



Acceptance around grieving, I
hated how uncomfortable my pain
made everyone feel

What do you want to see
change?

Type something...

People need to be more educated
on how to approach someone
who is grieving



Year Two



The work completed over the last twelve months has given us the building blocks to create a vision of future support for childhood bereavement.

Throughout year two of the project, we will continue to roll out our engagement strategy across Scotland. This will include hosting the remaining four roundtable discussions exploring the themes of 'Training & Education', 'Rebuilding Lives', 'Responses to Grief', and 'Mapping Support'. We will also engage with as many individuals with lived experience of childhood bereavement as possible, to inform and design our Timeline of Support. This will allow both for greater depth to our findings and greater clarity on the recommended actions that will form the basis of the project's final report.

The project is also working proactively to improve service provision when it can now, rather than waiting until final publication of the report. This includes breaking down barriers to accessing support across Scotland in collaboration with Cruse Scotland and Child Bereavement UK by strengthening the signposting website 'At A Loss'¹².

During the final months of the project we will focus on enhancing public understanding of childhood bereavement to prepare Scotland for the recommendations outlined in our final report.

¹² https://www.ataloss.org/?gclid=EAIaIQobChMI64WRyJLT8AIVB-WHmCh1PTAhzEAAAYASAAEgIXnvD_BwE



Thank You



We would like to thank the children, young people, supporting adults and individuals from organisations who have shared parts of their journey and are partnering with us to drive change together. The first year achievements of the National Childhood Bereavement Project are a direct result of that determination to make a difference for grieving children and young people in Scotland





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