

Identifying needs and mapping services

DEVELOPING CHILDHOOD BEREAVEMENT SERVICES

Finding out what kind of demand there is for your service and how it fits with other services in the local area is a key step in developing your service. This kind of exercise can confirm there is a real need for the service and provide you with useful data for approaching funders. It will also give you valuable information on how best to meet the needs and expectations of the people who are likely to use the service you are setting up. This factsheet gathers the experiences of Childhood Bereavement Network subscribers on ways of identifying needs and mapping service provision.

Why do you want to set up a service?

Before getting into any detailed analysis of local needs and available services, it can help to write down what it was that made you see the need for a childhood bereavement service in the first place. It may have been personal experience, a newspaper article, frustrations as a practitioner, conversations with a colleague or knowledge of a family not being able to find appropriate support for their child. Doing this can help to define the vision for your service, if you have not already done so. It should also inform the kinds of questions you need to find answers to in your needs analysis and service mapping exercise to give you a more comprehensive picture of:

- | the people you want to help
- | the kind of services and support they want and need
- | the range and availability of services already operating in the area.

There are a number of benefits in carrying out this kind of research.

- | You can check out your vision and make sure you are on the right track. If you are not, you can revisit your vision for the service and tailor your service model accordingly.
- | Supporters (including funders) will want to know that your service is offering something necessary and not duplicating existing provision.
- | You need to know there is a need for your service to keep your momentum and enthusiasm going.



Childhood
Bereavement
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The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK. We underpin our members' work with essential support and representation: bringing them together across localities, disciplines and sectors to improve bereavement care for children. Collectively, we share a **vision** that all children and young people in the UK, together with their caregivers, can easily access a choice of high quality local and national information, guidance and support to enable them to manage the impact of death on their lives. See childhoodbereavementnetwork.org.uk for more information and details of how to join. In this series of factsheets we have worked with local services and other stakeholders to gather information and practical advice on key topics for those interested in developing childhood bereavement support services.

- | It can provide useful background information for your monitoring and evaluation activity, for example by giving you information on what the local situation was like before you set up your service. You will be able to use this information later to draw conclusions about the impact and reach of your service.

Identifying levels of need in the local population

Why? This exercise will satisfy yourself and others that there is a real need for your service. It helps to be as knowledgeable as possible about bereaved children and young people in your area, and what their needs and expectations are.

Useful things to explore are:

- | approximately how many bereaved children and young people there are locally
- | the proportion of bereavements through sudden and expected deaths

- | what kind of issues they are likely to face
- | what kind of support they are likely to benefit from
- | what kind of short and long term impact this can be expected to have
- | whether particular local circumstances might affect how you deliver your service (e.g. travel arrangements)
- | population data which will give you information about the cultural, language and faith needs of the people you are aiming to serve.

How? There are a number of methods you might use to obtain this kind of information,

- | gathering statistics
- | undertaking a survey
- | carrying out a consultation.

See more information about these below.

Box 1: Useful sources of statistical information

There is a lack of comprehensive official data on childhood bereavement. CBN is lobbying government to collect and report on the incidence of bereavement in childhood, in the way that they do on the numbers of children affected by parental divorce.

In the meantime, CBN has published estimates of the number of children in each local area who are bereaved of a parent each year, and the local population of school age children who have been bereaved of a parent or sibling. See childhoodbereavementnetwork.org.uk/research/local-statistics

You will find useful information on the needs of children and young people in the publication 'Bereavement in Childhood – what do we know?' that is available to members of CBN

You could try contacting your local registrar to discuss collection of statistics locally. You can find their details on your local authority's website. Let us know if you are successful.

Information on premature mortality in local areas – deaths that are likely to affect children and young people – is available from:

- | Public Health England healthierlives.phe.org.uk/topic/mortality
- | the Northern Ireland Statistics and Research Authority nisra.gov.uk
- | Public Health Wales publichealthwales.nhs.uk
- | National Records of Scotland nrscotland.gov.uk (search under Deaths).

The police may be able to provide statistics on the number of deaths through road traffic incidents. Your mapping exercise (see below) may provide some estimates or proxy indicators from other practitioners or agencies working with bereaved children and their families. There is a big focus on local needs assessment in the development of services for both children and adults. Try and obtain a copy of your local Joint Strategic Needs Assessment or similar plan. See if there is an opportunity to influence these exercises in future, so that the kind of information you are seeking is collected routinely as part of a coherent local exercise.

Finding out what was needed – the Saying Goodbye Project

Kingston Bereavement Service was established in 1998 as a 1:1 counselling for adults. The service was getting an increasing number of enquiries for support for children and young people, and so in 2002 an application was made to Comic Relief who gave a £3,000 grant for research in this area. After a series of developments and more grants, there was enough money to appoint me as part-time (24.5 hrs per week) project coordinator in April 2016. I was recruited to develop and coordinate a new project for children and young people: the Saying Goodbye project.

The rest was a blank canvas, so I set about local research and networking, consulting with other organisations across the country, and setting up an advisory group. Locally, I developed a questionnaire for schools which asked them about the number of children they were aware of who had been bereaved in the last year, what support the school had been able to offer, where they had referred children on to, and what the school might find helpful from the Saying Goodbye project in the future. Thinking ahead to the resources we would need once up and running, I also asked if they had a room in which we could see children.

It was important to get parents' views too, so I went back through KBS' records and sent a questionnaire out to former clients who had children. I asked about the support they would have liked for their child at the time, and also asked if they would be happy to talk to me further. I had in-depth follow up conversations with three parents.

I also went to visit other services around the country to get a flavour of different support models. I visited a hospice with an 'open access' service, an independent county-wide children's bereavement service, an NHS-funded service and a children's hospice that supported siblings of patients who had died. I also visited another borough-wide service that supported both adults and children: the same as the model we expected to develop. I asked each of them a long list of pre-prepared questions about their history, philosophy, processes and policies, which gave a useful structure for when I came to make decisions how our service would look.

Finally, after all these conversations, we came up with a service structure that addressed the local needs we had identified and which drew on best practice in other services.

Mapping services already available

Why? This part of the exercise will help you find out what's already available in your local community and build up a clearer picture of the needs of your local population by drawing on the knowledge of those already working with them. Doing this part of the exercise thoroughly will bring a number of benefits. In particular, it will give you:

- | qualitative and quantitative information on what other services exist and are planned for the future (this will help you to avoid duplicating other services or competing for funding and service users)
- | contact with potential referrers who can give you more knowledge of the needs of bereaved children and families in your area, for example what support they already receive, what their main issues and concerns are and what existing providers think about the scale of the issue and how it could be addressed
- | confidence and support that you are working in an honest and open way
- | an idea of the potential level of referral to your service, to help you budget effectively
- | a clearer picture of who is interested in and supports the concept of your service (they may be useful champions later).

Who? To start with you will need to find out which local agencies are in contact with bereaved children and are offering bereavement support. A good starting point is to draw up a list of all those agencies who are concerned with end of life or bereavement support provision, as well as those agencies who may – directly or indirectly – come into contact with bereaved children and their families. Use your local service directory, existing contacts and the internet to get contact details for education services, health services and others. This is a very broad field and you may end up with many potential contacts.

Box 2: Example questions for local service providers

1. Are you in contact with bereaved families at the moment?
2. If yes, how many do you come into contact with on a monthly/yearly basis? What proportion of your client base does this represent?
3. Do you offer bereavement support? If so, what does it involve and who do you offer it to? If not, do you have any plans to develop support?
4. To which other organisations do you refer bereaved children, if any?
5. Do you see a need for or benefit in any additional services for bereaved children and young people in the area – and if so, what?
6. Are there particular issues which affect how families in this area access services, for example transport?
7. Would you be interested in helping develop a new service – with time, money, expertise or other resources (for example accommodation or equipment)?

- | Education services span early years, primary and secondary education and educational support services provided by the local authority and academy trusts.
- | Health services span primary, acute, end of life and mental health care services for children and adults.
- | Other agencies are located across the voluntary, public and private sectors, for example charities, faith groups, social care services and funeral directors.

How? Start by devising a simple questionnaire. Some example questions are suggested in **Box 2**.

- | Think about what questions you want answered, then write them up using clear, accessible language.

Finding out about local provision – Living On Bereavement Service

It was through my work as a dramatherapist in schools that I first became aware of the need for bereavement support: my caseload was predominantly bereaved children and young people. The nearest support was a 40-minute drive away. As a professional, I wasn't aware of anywhere nearer that I could refer families, so I set about talking to other agencies to see what they knew.

I arranged meetings with colleagues at all the local agencies I could think of that might be working with – or searching for support for – bereaved children and young people. These included the local young carers' organisation, hospitals, and other services working with children and families, including those with life-threatening illnesses. I visited the local wellbeing service which provides triage to young people referred to Child and Adolescent Mental Health services. They all said the same thing, that easily accessible group support for bereaved children and young people was missing in the area. These conversations were helpful in identifying who might make referrals to a new service in the future.

The conversations also helped me to realise that there was a real lack of confidence among local professionals about talking to bereaved children and young people. Many worried that they didn't have the right skills for this. That made me realise that many children weren't even getting support from the professionals working with them every day – more evidence that our service was needed.

- Consider using an online tool, such as those provided by Survey Monkey [surveymonkey.com](https://www.surveymonkey.com)
- Compile a comprehensive mailing list, to help ensure that your responses are as representative as possible.
- Pilot your questionnaire with a few people or get some input from someone with research experience to check that your questions are objective and that responses will be unambiguous and easy to analyse.
- If possible, follow up with a phone call to ensure people have received the questionnaire, to answer any queries and to encourage them to respond. You could even complete the questionnaire over the phone with them.

Following this up with some more in-depth interviews with practitioners from some of the key agencies is likely to give you more descriptive information which can add a useful extra dimension to the survey data. For example you might wish to explore the range of needs and issues that bereaved children and families appear to be facing, what type of work is carried out with them, what the impact of this is at the moment, and why particular services might be helpful.

Getting the views of children and families

The information from the service mapping exercise should give you some indication of the kinds of services that professionals feel would be beneficial for bereaved children and families.

But remember the real experts are the children and families themselves. By building their participation into the philosophy of your service right from the start, you are more likely to ensure that it is relevant and appropriate to them. Moreover, children and young people want to be involved in making decisions that affect their lives. Participation empowers children and young people and helps them to manage their grief.

How? There are many ways of finding out what services bereaved children and families would like, using existing source material as well as original consultation work.

Existing sources

The CBN website includes stories from young people reflecting on their experiences. Young people also share their views on what has helped on websites including Hope Again hopeagain.org.uk, Child Bereavement UK childbereavementuk.org and Winston's Wish winstonswish.org.uk

CBN has also produced three videos that feature children and young people talking about the support they would have liked childhoodbereavementnetwork.org.uk/shop

Original consultation work

A good way of finding attendees for a consultation event is to write an article for the local paper, for example about

the impact of bereavement support, and inviting bereaved families to the consultation event as part of the article (but be prepared to offer them support, if necessary). Alternatively, consider doing some retrospective work with adults who were bereaved as children to find out about the support they would have liked.

Next steps

With all this information, you should have a clearer idea of what kind of provision is already out there, what is needed and how your service might provide it. This will allow you to refine your vision for the service you want to provide.

Revisit your service plan and be honest about the things that need to change in light of the information you have found. For example, if your mapping exercise has revealed an adult bereavement service in the area which is already experienced in working with children and is keen to formalise this work, consider working in partnership with them rather than going it alone. If bereaved children and families tell you that there is plenty of one-to-one support out there but what they would really like are opportunities to meet with others in the same situation, consider tailoring your service as a support and social network, with links into other agencies that people have said would be helpful.

Box 3: Top tips for needs assessment and service mapping

You may find that you incur costs in running a focus group, printing a manifesto or carrying out some of the other activities listed here. If you do not have funding to cover these costs, try contacting your local Council for Voluntary Service as they may be able to suggest local sources of seed funding.

Remember that consulting with members of the community about your planned service is likely to create some sort of expectation that the service will be set up in the near future. Make sure that you have planned how to deal with requests for support which come in before your service is up and running. It may help to draw up a short leaflet with sources of useful information and support for people to refer to in the meantime. It could include, for example, Hope Again hopeagain.org.uk, Child Bereavement UK childbereavementuk.org and Winston's Wish winstonswish.org.uk

These activities might all seem like a lot of work, but remember once the data is collected you can use it many times for many different purposes, and for a range of potential funders and supporters – you just need to keep it up to date. Consider visiting stakeholders and potential service users rather than sending out a questionnaire – this can have a higher response rate. If you want to quote from what children, families and others tell you, make sure you have their consent to do this.