

# Mapping evaluation of UK childhood bereavement services

## Findings from a recent study



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**Abstract:** This article reports a study of evaluation strategies and tools currently used within UK child bereavement services. Data were sought from a representative sample of services across the UK on the evaluations' users, the data requested, and organisations' existing evaluation strategies. The study found that child bereavement services were struggling with a considerable burden of demand for information from a range of users – chiefly funders and commissioners of services. However, a mapping exercise revealed that a considerable amount of the data required by evaluation users was the same, and that it was being obtained from evaluations that services overall were already undertaking. The most common forms of evaluation were post-intervention user satisfaction surveys of core interventions, using self-completion questionnaires. However, collection of basic data was limited and patchy, and evaluations of outcomes and organisational processes and reporting on the findings were less common. Based on these findings, the researchers propose the development of a set of common evaluation tools that could be used across all child bereavement services.

**Keywords:** Childhood bereavement services evaluation, outcomes, outputs, evaluation tools.

Whoever we are, when we engage with a UK childhood bereavement service we have an interest in knowing whether it 'works'. A parent or carer might want to know whether the service will be able to help their child manage the anxiety of separation during a school day. A worker in the service may want to know if it is making a lasting change to the families who express gratitude for the intervention. A young person might want to know if it has helped others find ways of coping with their overwhelming feelings.

This natural interest in a service's effectiveness probably hasn't changed much since the first services were established. What has changed is the context in which funders – providers of grants and contracts – make decisions about which services they will support or procure. Increasingly, they are less interested in a service's activities (outputs) and more interested in the difference those activities make (outcomes). While this can seem threatening

or burdensome to organisations more used to reporting their activities, perhaps this is simply a case of funders coming more into line with what users of services want to know – that is, whether it works.

The policy context for this increasing focus on outcomes has been well documented (see, for example, Ellis, 2009; Hoggarth & Comfort, 2010). Successive governments have responded to the rising costs of health, social care and other welfare provision by increasing competition and developing a commissioning culture. These have been informed – and stimulated – by a rise in evidence-based practice and performance management in public services. In children and young people's services, commissioning involves identifying the outcomes we want, analysing what the population needs to achieve these outcomes, and procuring and monitoring services that meet those needs. Grant-making trusts and individual donors also want to know that the projects they are funding are effective in making changes

to their target groups (Heady & Oliveira, 2008). To access both outcomes-based grants and contracts, services in the statutory or voluntary sector need to identify the changes they are trying to make (and why), and demonstrate how their activities will bring these about.

Heady and Oliveira (2008) argue that robust evaluation improves services as well as informing funding decisions. If services don't evaluate, they can't tell if they are achieving positive outcomes, or make informed decisions about how to develop their services, or even identify interventions that may be causing harm. Their report on voluntary sector services for children and young people with mental health and emotional difficulties concludes: 'When resources are stretched, evaluation is the first thing to go. This is frustrating because demonstrating effectiveness can often be a better route to securing better funding' (p72).

Children's and young people's services are attempting to address these issues. The 2008 independent review of child and adolescent mental health services (CAMHS) in England argued that embedding the routine evaluation of outcomes – while not without costs and other challenges – is 'an essential move in order to secure the consistent improvements in the development of practice that are necessary' (National CAMHS Review 2008, p93). It supports developments led by the CAMHS Outcomes Research Consortium, a collaborative initiative that promotes a model of evaluation that can be used routinely across services to produce data to inform service development. Other initiatives under way include a questionnaire that New Philanthropy Capital is developing for charities to measure children's well-being (Heady & Oliveira, 2008).

Within this wider movement towards more evaluation of outcomes, childhood bereavement providers have been evaluating aspects of their work since they were established (see, for example, Stokes, Wyr & Crossley, 1997; Eedle, 2003). Evaluation has long been regarded as a 'pressing issue' for child bereavement services (Rolls & Payne, 2003, 2004, 2007). This has become more urgent through the policy changes outlined above, and from a growing awareness among services of the need to justify and generate confidence in their work, and to support organisational and professional development.

In addition, there is a growing body of evidence that expresses dissatisfaction with the adequacy of existing tools for assessing bereaved children's support needs and measuring the changes that childhood bereavement services make – including those changes that children and their families themselves want – over a sufficient length of time (eg. Stokes, 2004; Christ *et al*, 2005; Rolls, 2007; Currier, Holland & Neimeyer, 2007; Sandler *et al*, 2008; Rosner, Krause & Hagl, 2010).

In response to some of these issues, funding was sought from the Clara Burgess Charity to explore the evaluation of childhood bereavement services in more detail.

## The study

The aim of the study was to map evaluations of UK childhood bereavement services by identifying:

- evaluation users (those who make use of or act on an evaluation (Øvretveit, 1998))
- evaluation questions that are being asked of services
- the range of evaluations currently being undertaken, or that have been undertaken across the UK
- the range of inputs, processes, outputs and outcomes that need to be evaluated, and
- how best these could be undertaken and by whom.

The study also aimed to identify some of the complex challenges involved in evaluating UK childhood bereavement services, and this forms the subject of another paper in this issue (Rolls, this issue).

The study involved consultation with two groups of 'experts': service providers offering interventions for bereaved children, and other experts, defined as organisations or people with experience of research and evaluation in similar areas.

Organisations and individuals providing bereavement support services were drawn from the current list of subscribers to the Childhood Bereavement Network (CBN) and other non-subscriber services identified through an earlier study. National organisations were asked to nominate a representative from a local service. To meet the requirements of the Data Protection Act, invitation letters were forwarded to the CBN for onward posting to CBN subscribers. A total of 86 of the 299 services and individual practitioners who were contacted agreed to contribute. They encompassed all categories of service and ensured methodological validity. Other experts ( $n = 23$ ) were identified from among those already known in the field of bereavement and childhood studies, and from the UK literature on related areas.

The study was sponsored by the University of Gloucestershire. Ethical approval was given by the South West Multiple-Centre Research Ethics Committee. Permission of their respective NHS Local Research and Development Offices was obtained for NHS employees.

## Methods

Six focus groups of participants from child bereavement services across the UK were held in England and Scotland, and formed the central plank of the study. These generated extensive data that were collated and distilled into a single document detailing the main themes and issues discussed. In addition, two questionnaires were administered to participating services. Questionnaire 1 asked services about their organisation, provision and monitoring activity, as well as any evaluations that had been undertaken by them

or on their behalf. Services provided examples of evaluation instruments that they used. Questionnaire 2 asked services to comment on the focus group discussions, and to identify and prioritise aspects of particular relevance to them.

The returned questionnaires were anonymised through the allocation of a code number to ensure confidentiality. The closed questions were numerically coded, and a content analysis of any additional responses was undertaken and, where appropriate, added to the coding structure. Expert interviews were conducted in person or by telephone, and contemporaneous notes taken. Each expert interview was allocated a code to identify the interviewee’s comments.

### The current situation

The study generated a substantial amount of data, some of which is briefly outlined here.

### Who are the evaluation users?

A wide range of evaluation users were reported to be asking services for information, including:

- commissioners and policy-makers
- childhood bereavement services (service managers and practitioners, fundraisers and people considering working for a service)
- primary service users (children, young people and their families, and potential users)
- secondary service users and stakeholders, including referrers, schools and peers, local children’s services, academic institutions, and the media
- service developers, both national and international, and
- inspection bodies, with a slightly higher demand for inspections in the voluntary services (46%) than in the statutory services (35%). Services ‘embedded’ in a host organisation also had a higher level of inspection (49%) than did free-standing services (32%). Not all

respondents reported the frequency of these inspections but, of those who did, 13 reported one a year, six reported two a year, one reported three a year, and one reported four a year.

In addition, many individual practitioners said they were required to meet the accreditation requirements of their own regulatory bodies.

### What are evaluation users asking for?

The focus groups identified 51 questions that were being asked by these evaluation users, for which they had to generate data. These questions could be categorised under four broad headings: evaluation, information and monitoring, the use of the evaluation, and partnership/networking. The distribution of questions within these categories is shown in Table 1.

Across this range, services identified the most pressing questions as:

- what are the demographics of the service (in terms of, for example, age, sex of child, cause of death)?
- how effective is the service (does it work/meet needs)?
- what is the impact or benefit of the service?
- what are the outcomes, and whose are they?
- is the service meeting local needs?
- is it meeting and maintaining standards and guidelines?

### What evaluation data are services currently generating?

The study identified an extensive range of basic information and evaluation data that were being collected across all services. The greatest effort was focused on evaluating service interventions (84%) – particularly group interventions for children, group interventions for parents and individual work with children. There was less focus on evaluating outcomes (37%) or organisational processes

**Table 1:** Distribution of evaluation questions

Question type	Evaluation	Information and monitoring	Use of the evaluation	Partnership/networking
Service provision	7	10		
Governance		2		
Staffing	1	2		
Service outcomes	5	2		
Service users	1	3		
Evaluation users’ requirements		5		
Childhood bereavement		1		
The evaluation process		5	6	
Learning				1

(16%). Only 30% of respondents had explicit written outcomes for their service although they were not asked to clarify whether these were outcomes related to the aims of the service or to clinical outcomes involving observable changes in the child's bereavement trajectory.

Differences in the levels of evaluation activity were noted between different types of services. Voluntary sector services undertook more evaluations than those in the statutory sector across the three categories of 'interventions', 'outcomes' and 'organisational processes'.

### How are services undertaking these evaluations?

In total, 37 respondents described 114 instruments that they used to evaluate their interventions, outcomes and organisational processes, and 95 were submitted for scrutiny. The majority (84%) of the 95 instruments were used for evaluating service interventions, 13% for service outcomes and 3% for organisational processes. In addition, nine services also cited or enclosed 18 reports of published or unpublished evaluations that had been undertaken, either by them or on their behalf.

The majority of instruments (77%) focused on evaluating interventions in terms of user satisfaction: that is, 'how helpful' the respondent found the service (ie. how satisfied they were), rather than 'What helped?' and 'What has changed?' Nearly half (43%) focused on outcomes, in terms of what had changed or what benefits had accrued as a result of service use (a small number used the five outcomes of the UK policy programme Every Child Matters (HM Treasury, 2003) as a basis for their evaluation); 43% focused on the experience of using the service, and 4% on how the service was used.

The majority of the evaluation instruments (87%) were a post-intervention design – that is, they were completed post-session, post-group or post-service use. In total, 86% of the instruments were questionnaires for children, young people, parents and carers, and 7% used interviews and group discussions to collect the data. Half (51%) collected both qualitative and quantitative data (a mixed method approach), 22% collected qualitative data only, and 6% collected quantitative data only. One form had been devised by bereaved children. As well as having an evaluative purpose, the post-use evaluations appeared to provide a reflective activity for the service user, and formed the basis on which the provider tailored the next event. The remaining evaluations used a pre-post design (7%), or a case study and narrative analysis design (2%). As well as inviting service user reflection on how they felt immediately post-use, a number of post-use forms asked service users to reflect back on what they had felt like *before* the intervention.

The number of questions on any one instrument ranged from one to 46. Questionnaires were age-appropriate: for

example, younger children could draw or colour in an image, such as a body or a bull's-eye, to indicate some of the physical feelings or emotions they were experiencing, and Likert scales with 'smiley faces' were used for the child to indicate the level of their agreement. All the questionnaires were for self-completion but young children could be helped to complete the form by an adult, such as the service provider or parent.

### The mapping exercise

Mapping the information that the questions were designed to elicit demonstrated that most of the instruments were seeking very similar kinds of data. Six sources of data were identified that would generate answers to these questions:

- 1 service information – including internal information such as staffing, funding streams, purchasing processes and policies, and external information such as service history, mission statements, aims and objectives, service brochures and information packs
- 2 national or local statistics
- 3 basic data kept by the service on the characteristics of users and their service use
- 4 routine evaluations undertaken on a regular basis, such as pre-post evaluations of user satisfaction/outcomes
- 5 audits
- 6 in-depth evaluation studies.

Mapping the sources of the data provided demonstrated that a considerable amount came from evaluations that services were already undertaking.

### Areas for improvement

The study identified areas for improvement in evaluation strategy and technique. First, the collection of basic data and the range and type of questions on evaluation items varied and was, in some cases, limited and patchy across all the participating services. The majority of evaluation forms did not ask for basic information, such as the age and sex of the child, and so service providers had no means of interrogating the data more critically.

Second, there were gaps in organisations' evaluation strategies. Some services were not evaluating their full range of interventions; the most commonly evaluated were core interventions (the individual or group work with children and/or families). There was a lack of evaluation of service and/or clinical outcomes, and of organisational processes. Services were not routinely conducting pre-post evaluations of outcomes, although many services asked for users' reflections on the differences between when they arrived and when they left. Not all evaluation of training sought information about learning outcomes (even where a pre-test had been conducted). Then, having collected the data, services were not then analysing and reporting their findings.



Third, and most important, the diversity of evaluation forms used and the problems with the collation and analysis of the data made it difficult for many services to monitor their work over time, make claims about their impact, or compare themselves against the sector as a whole.

## A way forward

Based on these findings, the study proposed the following as a way of generating meaningful routine data without adding to the administrative burden of evaluation on services in terms of data collection, storage, analysis and report writing.

- 1 Strengthen current evaluation practice by improving the collection of key basic data; differentiating questions of satisfaction from those of outcome, and service outcomes from clinical outcomes; creating or reviewing a pre-intervention outcome form linked to the post-intervention outcome form, and post-intervention evaluation to include questions on satisfaction and outcome, and; improving the quality of the questionnaire design.
- 2 Develop an evaluation package for use across all services comprising a common basic data set, user satisfaction questionnaire, and clinical outcome evaluation measure.

Services could work with partner agencies to conduct larger-scale reviews, evaluations or research projects to obtain data to answer some of the more challenging questions – for example, the long-term impact of interventions and ‘What works for whom?’ – that are beyond the scope of a single service.

## Conclusion

This study highlights the extent of the evaluation challenge facing UK childhood bereavement services, and their responses. Overall, as a sector, childhood bereavement services appear to be extensively evaluated – mostly through post-intervention self-completion user satisfaction surveys of core interventions. However, collection of useful basic data was limited and patchy, and there appeared to be less evaluation of outcomes or organisational processes, and little formal reporting on the findings (as distinct from responding to evaluation users’ requirements for information). The development of a common set of tools to conduct routine evaluations would enable providers to monitor their own services over time, and would also produce data from across the whole sector on the impact of UK childhood bereavement services. Funding is being sought for this. ■

## Acknowledgements

With thanks to all participants, and to the Clara E Burgess Charity, who funded the study.

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