

MAPPING EVALUATIONS OF UK CHILDHOOD BEREAVEMENT SERVICES

EXECUTIVE SUMMARY

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The views expressed in this Report are not necessarily those of the Clara Burgess Charity or the University of Gloucestershire.

EXECUTIVE SUMMARY

This study was funded by the Clara Burgess Charity to map evaluations of UK childhood bereavement services over a period of one year – November 2006 to October 2007. It represents part of on-going funded research work with UK childhood bereavement services, as the principal researcher had undertaken earlier studies on childhood bereavement services funded by the Clara Burgess Charity. The funding for this study allowed for the appointment of a principal researcher (0.6 fte), a research assistant (30 hours) and a research administrator (0.2fte).

BACKGROUND TO THE STUDY

UK childhood bereavement services are a relatively new form of provision for children. Since their inception, services have undertaken some form of evaluation. However, the services involved in the original Clara Burgess Charity research project identified the pressing issue of evaluation (Rolls and Payne, 2003; 2004; 2007). Following discussion with the Childhood Bereavement Network (CBN), the Clara Burgess Charity was approached to fund a one-year study to 'map' current evaluation practice.

AIMS OF THE STUDY

The aim of the Mapping study was to identify:

- The key issues involved in evaluating UK childhood bereavement services;
- The range of evaluation currently being, or which had been, undertaken in services 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.

METHODS

The study, for which the ethical approval of the NHS South-West Multiple-Centre Research Ethics Committee, and the permission of the respective NHS Local Research and Development Offices was gained, adopted a Delphi design involving consultation with two groups of 'experts':

1. UK childhood bereavement services, defined as those providing a service for bereaved children;

2. Other experts, defined as organisations or people with experience of research and evaluation in similar areas.

Two hundred and ninety-nine services and individual practitioners were invited to participate. One hundred and eight replies were received giving an initial response rate of 36%. Of these 86 services participated in the study, who were drawn from a wide range of service types and characteristics, ensuring representation of all categories. Six Focus Groups were held across England and Scotland, two questionnaires were administered to participating services, and 22 interviews with other 'experts' were undertaken. The Focus group discussions were fully transcribed and imported into NVivo (a computer-based qualitative data management package). Data was coded in three stages:

- Within each Focus Group;
- Across the Focus Groups: the range of evaluation users was identified and the associated questions and purpose coded within each category of user;
- Across categories of evaluation users: the range of questions and purpose was identified.

Questionnaire data was entered into SPSS (a statistical package for social sciences) and a descriptive analysis undertaken. Interview notes were fully transcribed. Themes were identified from within the text, the study questions, and the concepts and categories used by other authors in evaluation literature. These elaborated the complex issues involved in evaluating childhood bereavement services, and identified a number of solutions.

SUMMARY OF FINDINGS

1. There is a paucity of evaluation literature on UK childhood bereavement services. Services have little evidence upon which to draw, or in which to situate their own service.
2. Services continue to be developed, and the volume of 'on-going cases' appears to be increasing. This signifies a rising workload that place limits on the capacity of services to undertake major evaluations. It also reveals the extensive experience of the sector in working with bereaved children.
3. There is a burden on UK childhood bereavement services, arising from the increasing volume and complexity of demand – common to a wide range of evaluation users – for evaluation and written policies and specifications. Meeting this level of demand requires extensive data collection and analysis, and report writing on the part of services.
4. UK childhood bereavement services appear to be extensively evaluated in terms of the quantity of evaluation. The majority of these evaluations are post-intervention user satisfaction surveys in the form of self-completing questionnaires.

5. Voluntary sector services undertook a greater level of evaluation across the three categories of 'interventions', 'outcomes' and 'organisational processes'. Furthermore, they undertook evaluations in more categories and they evaluated the four most frequently evaluated interventions more frequently than the statutory sector services.
6. The greatest evaluation effort was directed towards evaluating '*How helpful*' the respondent found the service (i.e. how satisfied they are), rather than on '*What helped?*' and '*What has changed?*' The greatest effort was made to evaluating group interventions for children, group interventions for parents, and individual work with children
7. There appeared to be deficits in evaluations in terms of evaluations of the:
 - Full range of interventions offered by a service;
 - Service and/or clinical outcomes, and formal evaluation of organisational processes;
 - Pre-post evaluation of outcomes;
 - Collated and written findings.
8. There appeared to be a number of additional issues that needed to be addressed:
 - The collection of Basic data questions on evaluation items was limited and patchy.
 - There would be difficulty for many services to:
 - Monitor their work over time, or make comparisons (benchmark) with others;
 - Analyse and collate data because of a lack of clarity about the focus to the questionnaires.
9. The priority perspective sought was that of the child. However, services were aware of the necessity of making a strong evidence-based case to politicians, the media, and service commissioners and funders. The priority questions identified were:
 - Evaluation Questions about outcome: '*How effective is the service?*' and '*What is the impact/benefit?*'
 - Information/Monitoring Questions about:
 - Service outcomes: '*What are the outcomes and whose are they?*';
 - Service users: '*What are the demographics?*'
 - Governance: '*Are you meeting/maintaining standards/guidelines?*'
10. A considerable number of all questions, including these priorities, would be answered through evaluation strategies that UK services *overall* are already undertaking.
11. There are a number of challenges arising out of the diverse and complex nature of the settings of UK childhood bereavement services, and the problematic nature of evidence and evaluation in social settings.

SUMMARY OF RECOMMENDATIONS

1. Strengthen the existing Basic data set and the existing Evaluation questionnaires by drawing on the range of data and questions being asked across all services;
2. Develop a common-core evaluation package to include:
 - A common Basic data set
 - A common-core User Satisfaction questionnaire
 - A common-core 'clinical' Outcome evaluation measure, either by
 - o Entering into further discussions/negotiations with CORE IMS; or
 - o Independently determining common core 'clinical' outcomes.
3. Engage in partnership for larger literature reviews, evaluation or research projects by:
 - Prioritising the identified research needs and locating appropriate partnerships to develop in-depth evaluation and research protocols and funding bids;
 - Identifying other questions requiring research studies and/or large-scale funding.
4. Assist future research on UK childhood bereavement services by:
 - Collating data in such a way that it can be used by researchers or can be 'sub-contracted' out for analysis
 - Developing the CBN membership database to include agreed and consistent fields and service categories;
 - Lobbying for research funding for evaluation of childhood bereavement services,
 - Influencing epidemiological/longitudinal studies to include childhood bereavement as a variable;
 - Developing links with academic institutions/research departments in fields of palliative care, family and child studies, and evaluation, for partnership work;
 - Increasing submission of research on UK childhood bereavement services to peer-reviewed journals;
 - Contributing to the production of evidence by having systematic review criteria in mind in research and publications.
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5. Developing a service research/evaluation culture.
6. Ameliorating the impact of competing agendas through the use of reference groups, focusing on the outcome agenda of children, identifying the purpose for which the evaluation will be used; and strengthening report writing.