

Childhood Bereavement Services: Proving your Worth



Last updated 30 August 2011.

CBN has produced this paper to help childhood bereavement services prove their worth to local and national government, by showing how their interventions are cost-effective and meet policy priorities.

As the government prepared for the Comprehensive Spending Review last autumn, the Treasury produced a set of nine questions to ensure that spending departments focused on which services are essential and how they can be provided most effectively and efficiently. New Philanthropy Capital www.philanthropycapital.org recommended that charities should try and answer these questions about their own services, so that they can talk to local authorities in the language that government is currently using, and strengthen their case in the face of cuts. Their report *Proving your Worth to Whitehall* gives an example of completing the questions on behalf of Volunteers in Child Protection, a project run by Community Service Volunteers.

This paper has been organised around those nine questions and gives some suggested content. You will have plenty more ideas – please do contact Alison Penny on apenny@ncb.org.uk if you have any suggestions you'd like to add to this paper.

We will keep an updated version of this paper in the Policy and Practice section of the CBN website at http://www.childhoodbereavementnetwork.org.uk/policyPractice_policy.htm

1. Is the activity essential to meet government priorities?

There is a number of government documents that you can quote to show how your activities meet the priorities outlined.

Children and young people's mental health

- *Children and Young People in Mind* (2008) <http://www.dcsf.gov.uk/CAMHSreview/>, the report of the Independent Review of CAMHS, listed the groups of children and young people included in their use of the term 'vulnerable' – this included children and young people who have been bereaved. 'These are groups that service managers, providers and commissioners need to ensure they consider and plan for' (Annex E p116)
- *Targeted Mental Health in Schools – Using the evidence to inform your approach: a practical guide for head teachers and commissioners* (2008) <https://www.education.gov.uk/publications/eOrderingDownload/00784-2008BKT-EN.pdf> summarises existing knowledge about effective interventions to help make decisions about how to plan and commission work. Section three covers the evidence on targeted interventions for children in five sets of circumstances that pose a risk to mental health. Childhood bereavement is covered in some depth.

- *Standard 2 of the National Service Framework for Children, Young People and Maternity Services: Supporting Parents* sets out that local health, education and social care agencies should provide information to parents on services to support them and their children through disrupted relationships and bereavement (sec 4.2, p71). It also says that PCTs, local authorities and the voluntary sector, working in partnership with providers, need to ensure that local planning addresses the needs of parents who are experiencing problems as a result of disrupted relationships and bereavement (sec 6.5, p76)
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090556.pdf
- *Standard 8: Disabled Children and Young People and those with Complex Health Needs* sets out that paediatric palliative care services should provide high quality, sensitive support that takes account of the physical, emotional and practical needs of the child or young person's family, including their siblings (sec 5.15, p33). Following the death of a child, whether sudden or anticipated, families should receive ongoing support to cope with their loss (sec 5.18, p35)
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090556.pdf
- *Promoting social and emotional well-being in primary education (2008)* sets out the National Institute for Clinical Excellence's formal guidance. It includes recommendations that staff in schools should be trained to identify and assess early signs of anxiety and emotional distress, including among children who are at higher risk including those who have been bereaved. They should be able to discuss options with the child and their parents, make appropriate referrals and provide an appropriate range of interventions. <http://www.nice.org.uk/Guidance/PH12>

End of Life Care

- *Department of Health End of Life Care Quality Markers*
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf
 - 1.15 Local Authorities to ensure that the needs of carers are appropriately assessed and record through a carer's assessment and that support is offered pre- and post bereavement.
 - 1.31 Commissioners to ensure that providers have assessed the needs and provision for bereavement services, including support for children.
 - 3.10 Hospitals to assess the needs of families and carers and provide them with appropriate support during the patient's time in hospital and in the period around death, if the patient dies in hospital
- *Department of Health draft quality markers for bereavement support*
http://www.endoflifecareforadults.nhs.uk/assets/downloads/Draft_Spiritual_Support_and_Bereavement_Care_Quality_Markers_1.pdf
 - 1. Commissioners to demonstrate the following: that a local service specification for bereavement services has been developed in partnership with acute, community, voluntary and private sector providers and local authorities. It is suggested that this includes the provision of specialist support for all sections of the community as identified in a local needs assessment, including vulnerable groups such as children and

those with learning difficulties. Commissioners will wish to consider having effective monitoring systems in place to ensure that services are commissioned in line with, and comprehensively cover, the service specification.

2. Providers to demonstrate the following: Bereaved people are offered immediate, and culturally and spiritually appropriate, support at the time of death, and shortly afterwards. Accessible information on the experience of bereavement is provided to the bereaved, and they are directed to the local and national support services available, including sources of financial and practical help, in line with guidance set out in *When a Patient Dies* and UK Standards for Bereavement Care.
 3. Providers to demonstrate the following: That effective pathways are in place for the identification, provision of emotional support, and appropriate onward referral of those at increased risk of, or currently experiencing, a complicated or prolonged grief reaction, for example as a result of a sudden death, or a young or vulnerable person losing a parent.
- *National Institute for Clinical Excellence draft Quality Standard for End of Life Care*
<http://www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp?domedia=1&mid=B7C38F4D-19B9-E0B5-D477151ADF086A21>
 9. People approaching the end of life and their carers and families receive emotional, spiritual and religious support appropriate to their needs and preferences
 18. People closely affected by a death have access to emotional and bereavement support appropriate to their needs and preferences
 - The National Institute for Clinical Excellence *Improving supportive and palliative care for adults with cancer* (2004) recommends a three-component model of bereavement support, including specialist interventions for children and young people (sec 12.30). <http://guidance.nice.org.uk/CSGSP>
 - The *Liverpool Care Pathway* now includes links to information for children and young people facing the death of someone important in their lives <http://www.liv.ac.uk/mcpil/liverpool-care-pathway/documentation-lcp.htm#Supporting%20Children>
 - The government's response to the *Palliative Care Funding Review* is still awaited. The final report of the review acknowledges CBN's evidence that bereavement services for children are not currently universal, and states that 'we do think it is important that universal access to these [bereavement] services is available for everyone if they need them' (p57).
<http://palliativecarefunding.org.uk/wp-content/uploads/2011/06/PCFRFinal%20Report.pdf>

2. Does the government need to fund it?

The evidence given in response to the other questions will help government to decide whether this service is worth funding.

3. Does it provide substantial economic value?

Increasing investment in services which intervene early in children's lives when problems emerge is recognized to be an important way of making cost savings in the future. It is always difficult to

calculate the cost savings of programmes which are essentially preventing the emergence of more serious difficulties and their associated individual and societal costs.

In the case of childhood bereavement services, these difficulties are compounded by the diversity of service delivery models across the field – including differences in the ratio of paid staff to trained volunteers; differences in family sizes; differences in the needs of individuals between and within families. Some families will manage well following a series of reassuring telephone calls, others will need more intense face to face support. Some will access the service once, while others will make use of the ‘extended warranty’ and come back to the service for more help at times of future change.

There is no cost-benefit or cost-effectiveness analysis of childhood bereavement services that we know of. This would calculate all the costs of providing a childhood bereavement service, against the total benefits to society which that service brings through the outcomes it effects. It is easier to calculate the cost savings which a childhood bereavement service brings, eg

- £2320 if it improved the child’s attendance at school over four months avoiding the need for intervention from a Education Welfare Officer
- £2740 if it avoided the need for the child’s involvement with a Tier 2-3 CAMHS (Child and Adolescent Mental Health Team)
- 6,000 if it avoided the child being permanently excluded from school for a period of 4 months.

These costings are based on the National CAMHS Support Service’s cost avoidance calculator for Targeted Mental Health in Schools work, eg <http://www.londonhp.nhs.uk/wp-content/uploads/2011/03/Mainstreaming-TaMHS-costs-avoidance-Swindon.pdf> CBN is currently developing a similar calculator for child bereavement services and will add in other potential cost savings.

In the meantime, you can do a useful comparison between the costs of delivering your service with the costs of delivering a comparable intervention.

Calculate the costs of delivering your service to an individual child or young person. Add together all the costs of your service including salaries and on costs, project costs, overheads, travel expenses and any other relevant expenditure, and divide it by the number of children and young people you worked with last year, to give a very rough ‘per head’ costing for your service.

Once you’ve done that, you can compare the costs of delivering your work with similar activities. Here are some examples we found

- The Personal Social Services Research Unit (PSSRU) at the University of Kent has estimated the average cost per case per team in CAMHS services. Generic single disciplinary child and adolescent mental health teams (CAMHS) operate at Tiers 2-3 and are staffed by one clinical profession – generally clinical psychologists, educational psychologists or other therapists, or primary mental health workers. Their average cost per case per team is £3,384, excluding administrators and managers. Generic multi-disciplinary CAMHS teams also operate at tiers 2-3, and their average cost per case per team is £3,735, again excluding administrators and managers. <http://www.erpho.org.uk/viewResource.aspx?id=20737> pp160-161

- The Department for Education estimates it costs on average £2955 for a parent to complete a Parenting Early Intervention Pathfinder group. (Based on costs of delivering Incredible Years, Triple P or Strengthening Families: Strengthening Communities programme to group of parents of 8-13 year olds) <http://www.education.gov.uk/research/data/uploadfiles/DCSF-RW054.pdf>
- The National Institute for Health and Clinical Excellence estimates it costs £2,000 at a clinic and £3,000 in a family's home to deliver a parenting training/education programme - of 2 hours per session for 8 sessions - on managing children with conduct disorder. Costs include staff time of one facilitator being paid health visitor or equivalent salary, supervision, transport, childcare and course materials. <http://guidance.nice.org.uk/TA102/CostingReport/xls/English>
- Delivering the above programme to a group of 10 parents costs £5,000 in a clinic and £7,200 in the community (ie £500/£720 per parent), for 10 sessions of 2 hours per session. Costs include staff time of 2 facilitators being paid health visitor or equivalent salary, supervision, transport, childcare and course materials. Training of facilitators (including costs to replace them in their usual daily activity) is an additional £1025 per facilitator. <http://guidance.nice.org.uk/TA102/CostingReport/xls/English>
- The National Institute for Health and Clinical Excellence recommends that children and young people who have mild depression should, after a period of up to 4 weeks of watchful waiting, be offered individual non-directive supportive therapy, group CBT or guided self-help for 2-3 months. It estimates that the cost of 12 sessions of intensive therapy for children and young people with depression is £616, and a course of group CBT (average 8 people, 16 sessions of 2 hours) is £1792 (or £179.20 per child). These are calculated on a cost of £56 per hour of clinical contact.
- It recommends that children with moderate to severe depression should be offered individual CBT, interpersonal therapy or shorter-term family therapy of at least 3 months duration ie an average of 15 sessions. They estimate the costs of this to be £840, based on a cost of £56 per hour of clinical contact.
- The above two calculations were based on a cost of £56 per hour of clinical contact – including wages, salary, on costs and capital costs. However, the updated *Unit costs of Health and Social Care 2009* from the Personal Social Services Research Unit (PSSRU) at the University of Kent <http://www.erpho.org.uk/viewResource.aspx?id=20737> now estimates clinical contact for cognitive behaviour therapy to be £64 per hour.
- PSSRU estimates that a clinical psychologist costs £34 per hour, £77 per hour of client contact, £44 per professional chargeable hour (Including salary, on costs and overheads) <http://www.erpho.org.uk/viewResource.aspx?id=20737>
- PSSRU estimates that the costs of a family support worker (based on a worker supporting carers of people with schizophrenia, and including salary, on costs, overheads and training) are £39 per hour of client related contact (£42 in London)

- PSSRU estimates that counselling services in primary mental health care (salary, salary oncosts, overheads (direct and capital) cost £42 per hour of client contact <http://www.pssru.ac.uk/pdf/uc/uc2009/uc2009.pdf> p67

Looking beyond interventions at some outcomes for children and young people:

- New Philanthropy Capital estimates that the total (lifetime) cost to individual and society of an exclusion from school in 2005 was £63,851 (including health, education, lost earnings, crime, social services). <http://www.philanthropycapital.org/download/default.aspx?id=352> p12
- The same lifetime costs of persistent truancy were estimated at £44,468.
- The New Economics Foundation estimates it costs £100,000 per year to imprison a young offender http://www.neweconomics.org/sites/neweconomics.org/files/Punishing_Costs.pdf

4. Can it be targeted at those most in need?

CBN believes that *all* children have the right to information, guidance and support to help them manage the impact of death on their lives. However, we know that bereavement may have particularly harmful implications for those already vulnerable or living in disadvantaged circumstances (Ribbens McCarthy with Jessop 2005).

In your answer to this question, you can talk about any targeting of your service, eg

- Families being assessed through the Common Assessment Framework and referred to your service via a Multi-Agency Panel
- Specific outreach and awareness-raising activities you do to professionals and groups of children and young people eg to those looked after by the local authority, those involved with the youth offending team, those with drug or alcohol problems
- Specific outreach and awareness-raising activities your service that you do in disadvantaged neighbourhoods – is those which have a higher mortality rate than average.

5. How can it be provided more cheaply?

Perhaps begin your answer with how your service is *already* being provided more cheaply than it might – eg through your use of volunteers, good relationships with other community groups who let you use their premises cheaply or print your newsletter at a discount. If you use volunteers, you can cost out what you would have to pay to employ people at the same level of skills and abilities, and demonstrate this as a saving. If you think you can provide your services more cheaply, you can mention it here. Examples might include

- Using more volunteers both in administrative roles and direct work – but remember that using volunteers incurs significant costs in training, support, travel costs etc
- Providing some services on a group basis rather than to individuals – but make sure this fits with your service's ethos and the expertise of paid staff.

- Sharing back-office functions with other charities or organizations

6. How can it be provided more effectively?

Here you can say something about how effective you know your service to be already – using any evaluation data or other evidence from impact assessments you have carried out. Describe anything you have already done to make your service more effective. You can also mention that CBN is seeking funding to develop a pre- and post- intervention outcome tool for the sector, and once this is developed and embedded in services it may help individual services make decisions about how to be more effective.

7. Can the activity come from a non-state provider or by citizens, wholly or in partnership?

In at least 85% of cases, it already does (Rolls and Payne, 2003)! If you are based in the voluntary or community sector, set it out here, along with any examples of how your service involves the local community eg through recruiting volunteers, fundraising, publicity etc. Point out how this level of community involvement actually makes your service more efficient as it means that families who might need you are more likely to be aware of you.

If you believe that families are more likely to use your service because it isn't provided by the state mention it here: this will demonstrate that your flexible, responsive approach is less stigmatizing, pathologising and ultimately more effective than a state provider could be, as more families will engage.

You can also mention here any important links you have with state providers eg CAMHS services, social services, schools etc, and how you are adding value to the work which they do.

However, make it clear that you still need funding to do the work, and that the local authority and PCT should be working together to commission services such as yours.

8. Can non-state providers be paid to carry it out according to the results they receive?

Payment by results would be very difficult for many small voluntary and community sector organizations, as they do not have the financial stability to undertake work before they are paid for it. Both the provider and the funder need to be absolutely clear about whether the 'results' that will be measured will be activities (ie the things the organisation does, eg 10 group sessions) or outcomes (ie the changes the activities make, eg children are more able to tell the story of what happened). So be cautious about payment by results – take advice from your local Council for Voluntary Service (www.navca.org.uk) who will be able to advise about how your local authority is developing this work.

9. Can local bodies, as opposed to central government, provide it?

Explain how your service is delivered locally, and whether or not it has a relationship with central government.

References

Ribbens McCarthy with Jessop 2005 *Young people, bereavement and loss: disruptive transitions?*
London: NCB

Rolls, L and Payne S (2003) Childhood bereavement services: a survey *Palliative Medicine* 17, 423-432

August 2011