

Working with parents and carers of bereaved children and young people

Setting up a facilitated self-help group

By Frances Kraus and Stewart Sinclair, St Christopher's Candle Project

The Candle Project self-help group has been running since 1999 and was set up for the parents and carers of bereaved children. The Candle Project is run by St Christopher's Hospice in South-East London, to offer bereavement counselling and support for children and young people in the local area. It also provides training, advice and consultancy to schools and other agencies working with children facing bereavement.

Aims

Our aim was to provide a self-help group for parents and carers of bereaved children, to offer ongoing support in their family's bereavement.

Principles

A set of guiding principles informed the development of the self-help group. Others thinking about setting up a similar group may find it helpful to take these into account in their planning and development process:

- It can be daunting for parents and carers to deal with their child's grief on their own and sometimes they may feel they would like some help. A self-help group can be a valuable way of providing this help.
- There are lots of ways to support children. It can help to have the opportunity to explore and discuss these with others, but ultimately parents and carers should try to do what they feel most comfortable with, accepting that sometimes they will get some things wrong.
- The members are the most important part of a self-help group, but the group is most effective when it has a good infrastructure and support, in the shape of childcare, transport and staffing.

- A self-help group needs to be as representative as possible. For men thinking about joining, it helps to see other men involved as group leaders. The same is true for people from minority ethnic backgrounds.
- A self-help group needs to be open and welcoming to new members. It is important to understand why they want to access the group and how the group can help. At the same time, it is important to have procedures for dealing with the very rare instances of inappropriate behaviour.

How the group operates

The group meets three times a year on a Saturday in term-time from 1.30pm to 3.30pm at St Christopher's Hospice, with childcare provided. We offer help with transport if requested.

The groups are run by two former service users who are part of the Candle Project advisory group. They are supported by the paid staff and volunteers from the project. Candle undertakes all the administration, taking referrals, sending invitations, training and supervising the volunteers, arranging transport for members, and debriefing and supervising the group leaders.

Though we can only offer childcare provision at three group meetings a year, the group has always had the option of meeting without childcare. Meetings like this can take place several times a year and might involve going to a park for a picnic with children, out to a restaurant or club without children, or meeting at the hospice.

Candle publicises these additional meetings by sending out invitations and booking a room if meeting is on-site, but apart from that it has no other involvement.

Identifying the need

Many users of the Candle Project had asked for opportunities to meet other parents on an ongoing basis, so staff took the proposal to the advisory group. We presented our ideas and suggestions and asked for comments. They all felt that the initial proposal was good, and that it was sensible to start with three meetings a year so as not to over-stretch our resources. Our two former service users who sit on the advisory group offered to run the self-help group. This was felt to be more appropriate than a staff-led group, as well as a better use of our limited resources.

This leaflet is one of a series showing different models for working with the parents and carers of bereaved children and young people. The series aims to provide practical ideas and inspiration for others thinking about setting up services for bereaved families. Funded by the Parenting Fund, the series is produced by the Childhood Bereavement Network, a national federation of over 300 organisations and individuals and Winston's Wish, a national charity helping children and young people rebuild their lives after a family death.

Organisations represented on the Candle Project advisory group

- The Maudsley Institute
- Local child psychiatry service
- Child Death Helpline
 - for those affected by the death of a child
- St Christopher's Hospice
 - including a trustee (linking the group to the hospice management structure), the librarian, Candle Project staff and the Candle Project director (line manager of the project leader and also chief executive of hospice)
- Service users
- Local counsellor
- Local child psychotherapist

Once the advisory group had approved the proposal, we consulted with former and current users of the service by telephone or face-to-face. Their response was very positive, confirming the need and demand for the service. However this consultation did not alter our plans, which were dictated by our available resources - at the time, two part-time staff and a sessional worker. None of the respondents to the consultation asked for more input at that stage and no-one questioned the proposals. The overwhelming view seemed to be that people were grateful that the service was being developed. This may be indicative of a potential drawback to consultations - namely that it can be difficult to comment on something that does not yet exist.

After the consultation, we wrote a flyer to advertise the group and sent it to former and current clients we thought would be interested and suitable for the group.

We did not work with any other organisations in setting up the group. The primary reason for this was that no other organisation was providing the same kind of service. Most self-help groups for parents (for example Gingerbread) focus on parents who are single through divorce or separation. Our group was for parents who are single through bereavement, and this was bound to be a major focus of attention.

Getting started

Having decided to set the group up, there were a number of practical issues we had to sort out. These were:

- finding child-friendly, safe premises for the main group meetings, which provided:
 - outside space or easy access to it, as the children would need to go out and run about
 - a comfortable room for parents to meet
 - access to tea and coffee making facilities

- recruiting creative volunteers who could come up with ideas to entertain children
- ensuring a trained staff member was in charge of childcare and available before meetings to field any last minute issues
- organising transport
- assessing and introducing new members
- developing policies and procedures - for example a policy for dealing with inappropriate behaviour.

Staffing

There were three main areas in which we had to sort out staffing: providing a sessional worker for each main group meeting, recruiting volunteers to provide childcare during the group meetings, and recruiting ex-service users as group leaders.

Paid staff

One paid sessional staff member is required on a regular basis, to oversee the support provided at each of the main group meetings where childcare is offered and to supervise group leaders and volunteers. They have the responsibility of co-ordinating the arrangements for the childcare, which involves arranging volunteer attendance, helping them decide what activities to arrange for the children, and sorting out who does the shopping for the equipment or food. They also foster and assist the parent group leaders (see 'ongoing supervision' on page 3).

The sessional worker for our self-help group is a social worker and member of the Candle Project groupwork team. She attends the monthly team meetings and has monthly supervision.

In addition it is helpful to have other staff who can join in and cover for sickness if required.

Childcare volunteers

To provide appropriate childcare for group meetings we have found it necessary to have lots of volunteers to ensure a high adult:child ratio. We work on a basis of 1:2.

All Candle volunteers are expected to support one group meeting a year. However, because the number of children attending can be as high as 24, we often need to call on extra help from hospice staff. They are able to help out in offering childcare under supervision. They do not lead sessions.

All volunteers have enhanced Criminal Records Bureau (CRB) checks and work under the supervision of the sessional worker. All activities are group-based. The core group of Candle Project volunteers are recruited through local advertising. The additional volunteers needed for childcare are

recruited mainly through word of mouth, though we also put notices on the hospice notice board.

Parent group leaders

We have found that recruiting ex-service users is invaluable in running a successful self-help group. However there are some considerations to bear in mind:

- The group leaders need to have sufficient distance from their bereavement to be able to fulfil the role. When recruiting leaders, we have found it more productive to look for the positives in potential leaders than to wait for the 'perfect' person to come along. Though this is a natural tendency, such caution may mean that the group never gets started. As leaders adjust to their new situation they may function in a different manner to their 'norm' and their leadership qualities may need a little nurturing as they adapt to single parenthood. They may not always have the 'right words' to hand, but if their meaning and intent is clear, that is the most important thing. Over time, sensitive supervision usually irons out any difficulties.
- A gender and ethnicity balance is desirable. We have had more success in attracting and retaining men in the group when one of the group leaders has been a man. The ability of the group leader to transcend issues of class, culture, religion and ethnicity is also imperative in cultivating positive dynamics in the group. This process does not need to be infused with political correctness, it just needs to work!
- Expert supervision and management should be available to deal with the complex issues that self-help groups generate, for example when volunteer leaders, who themselves are vulnerable, are dealing with peers in a similar situation. We have just put a formal supervision process in place to help us retain group leaders and members. We think supervision is important after each meeting - i.e. three times per year. It could be delivered by any member of the staff team, but is probably most appropriately delivered by the worker who supervises the volunteers.

Training and support

Candle Project volunteers and our group leaders receive training and support of two main kinds:

- initial training
- ongoing supervision.

Initial training: Candle Project volunteers attend a 20-hour training when they join the project. It is worth noting that the additional volunteers who help out with childcare for the

self-help group do not attend the Candle Project training programme. They are interviewed by two staff, are CRB checked and then have a period of probation, usually their first group session.

Ongoing supervision: During our first years of operation, the sessional worker debriefed the parent leaders and also the volunteers after each group. For the reasons outlined above, we are now putting in place a more formal supervision structure for leaders and volunteers. The sessional worker is supervised by the Candle Project leader.

Having a good supervision process in place means that group leaders know they will be supported when something becomes too much for them to handle on their own, and that external to the group there is a formal process of support, as well as a safety-net.

In particular, leaders need to know that they are not making things worse for others and that they are not making things worse for themselves. The provision of skilled supervision is critical in this aspect of a group that is constantly dealing with death.

Another vital function of good supervision is to provide a bridge between a voluntary self-help group operating without formal policies and procedures, and the requirements and risk-assessments that surround formal practice. For example, if the group meetings indicate that there are serious concerns regarding issues such as child protection or mental illness for a participant, a formal mechanism is available to link the participant – via the volunteer leader – to the supervisor and ultimately to any necessary statutory services.

Referrals

Candle Project staff make referrals to the group from their own client caseloads. If parents ask to attend the group and are not known to the Candle Project, they are invited to meet with a team member.

This enables the service to form an assessment of their ability to use the group. The form and remit of the group is explained to them, and general feedback is given to the group leaders before the new member attends their first group.

Other issues to consider

We have tried to avoid making the group bureaucratic – this is important for any self-help group. Nonetheless, the reality is that issues around confidentiality, conduct and child protection do need to be addressed.

- We recommend establishing the boundaries of confidentiality in the inauguration phase of any new group. Everyone needs to be aware of what these are.

- It is likely that groups may at times find themselves with a member who appears unable to conform to conventional boundaries, to the extent that intervention may be necessary from the supervisor. Examples include members who are very demanding of group time and space, or who abuse the childcare facility. These can be the hardest of issues to resolve in the context of a self-help group. Even when it is well-managed, there is a residual burden of guilt on the group leaders, because they will be the people who have blown the whistle. Such issues are dealt with through a combination of group and staff action, coupled with supervision for group leaders.
- In case there is any 'fall-out' from such interventions, volunteer leaders need to know that their supervision framework will offer guidance, protection and if necessary 'absolution' as there may be a sense of betrayal when tackling sensitive issues.

Evaluation

A formal evaluation of our service is not compatible with the ethos of the group. We feel that members do not come to be evaluated, or to evaluate their experience of the group.

At the same time, those parent and carers who volunteer their time as leaders are unlikely to find the prospect of form filling rewarding, or fulfilling. They come for support and reassurance, so it is the task of managers – through skilful supervision – to evaluate how the group is evolving and progressing.

However we do have more informal procedures in place for documenting the life of the group. The group leader takes notes at each meeting. These are not 'minutes', but a record of those attending and the issues raised, to provide a thread of continuity in the long gaps between meetings.

They also provide a history or record of how individual members are adjusting to their loss. Common themes, such as school, childcare and housing and benefits are also noted. Having a record helps the group use its past experience to assess how to approach and respond to some of these issues.

Sensitive subjects such as new relationships are regularly discussed and recorded in the notes. This helps the group to develop its own 'dictionary' of the process of adjusting. This can become (and has become for us) an invaluable catalogue of emotions experienced in the grieving process. It helps regular members evaluate their own milestones in salvaging and rebuilding their lives. It gives comfort and

confidence to new members and offers a reference point for self-evaluation for everyone.

We usually refer to the notes at the start of each meeting as a reminder of issues relevant at the time. The notes are also very useful in filling in the gaps for people who have missed a meeting.

Cost

Most of the costs for this type of project are hidden, taking the form of volunteers' and group leaders' time and running costs such as accommodation, insurance and heating. However an estimate of the actual expenditure incurred is set out below:

Start-up costs	£	Total
Recruitment costs for new group of volunteers to support parents/ carers in group meetings:		
• administration time – advertising, chasing references etc.	40	
• 2 staff to interview 10 volunteers x ½ hour each	300	340
Training costs:		
• 2 staff train 10 volunteers for 2 hours @ £30 per hour	120	
• Staff preparation for training 6 hours @ £30 per hour x 2 staff	360	
• Administration costs of training 2 hours @ £10 per hour	20	500
Total start-up cost		840
Ongoing costs	£	Total
Staff sessional worker for each group meeting (6 hours from 11am to 5pm to supervise volunteers, co-ordinate activities, debrief group leaders and volunteers, plus 2 hours admin/phone calls to arrange shopping and volunteer cover):		
• 6 hours @ £25 per hour	150	
• 2 hours @ £10 per hour	20	170
Supervision of sessional worker:		
• 1 hour @ £45 per hour	45	
Administration time:		
• 4 hours @ £10 per hour	40	
Catering (for 6-8 volunteers, 8-14 members and 10-22 children):		
• Sandwiches, cakes, cost of equipment	50	
Transport (cost varies):		
• Approximately 3 return taxi trips per group estimated at £25 per round trip	75	
Total cost per group meeting		380

Training module for volunteer childcare workers

This is a 2½ hour module with a refreshment break. It is run by a worker who will manage volunteers. Input from a group leader is also very valuable.

Aims

- To raise awareness of needs of bereaved parents and children.
- To prepare and educate about how group meetings can meet some of those needs.
- To inform about child protection, health and safety and manual handling issues.

Objectives

- To enable volunteers to work successfully together to facilitate childcare activities in a safe, appropriate and entertaining form for children so that their parents can meet separately.

Learning outcomes

- Volunteers will have an increased understanding of the needs of bereaved families and the role the group plays in meeting these needs.
- Volunteers will have an understanding of relevant and appropriate procedures for working with children including child protection, health and safety and manual handling.

Outline programme

Part I: Bereavement and group support

20 minutes	Background to group: ethos of family-focused support, evidence from research, how group fits in to other work of the Candle Project.
20 minutes	What are the issues for bereaved parents? Brainstorm and group discussion, note issues on a flipchart.
10 minutes	How can a group help address these? Group discussion.
15 minutes	Break for refreshments. Parent group leader leaves after this.

Part II: Working with children

20 minutes	Input on value of group experience for bereaved children: feedback and other evidence, how this group fits in with other work of the Candle Project.
20 minutes	What are the likely problems? Group discussion. Worker to raise issues such as: ages/stages of children, restrictions of time/space, suitability of activities. Ideas welcome from volunteers, for example suggestions for activities (this empowers volunteers and makes them feel useful straight away).
20 minutes	Legal information. Input on the way the project keeps children, staff and volunteers safe. Handout on child protection policy, health and safety and manual handling.
15 minutes	Any last issues? Close session with an activity/game that might be carried out with the children.

Reflections on the Candle Project self-help group

We reflected on what it means to run a self-help group, focusing on the strengths, weaknesses, opportunities and threats for those involved (a 'SWOT' analysis). Although this is specific to our group, others may identify some areas they want to consider in more detail if they are thinking about setting up a similar model.

Strengths

- informal and easygoing
- weekend day makes it accessible to working parents
- people can bring their children with them and facilities are child-friendly, familiar and safe
- offers people opportunities to make friends/talk with people facing similar challenges
- individual progress can be monitored informally by staff and more focused support offered promptly if needed

Weaknesses

- group leaders must be consistent and reliable, which can be difficult for bereaved people
- we never know who/how many people are going to turn up, so it can be difficult for staff to know what level of support will be needed
- risk that there will not be enough people to keep things going in future
- new people always needed, but too many at once can unsettle group dynamic

Opportunities

- a self-development opportunity for ex-service users, who run and facilitate the group
- parents and carers can access childcare facilities as well as opportunity to talk to other adults
- transport is provided for members if necessary, so it is possible to reach a wide community of users
- leads to other social events organised by regular members during the year

Threats

- clash of personalities or conflict between group members
- group leaders not having the skills or support to deal with these situations – leaders need to be well supported and supervised to avoid this happening
- longstanding leaders can get burnt out or decide to leave and group could end if leaders leave – leaders and staff need to identify and prepare new leaders to avoid this
- group could run out of steam and people might stop turning up

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