Project Name: Kids Grief: A Handbook for Group Leaders

Reporting Period Final Report – due date 11/6/04 (extension granted)

Funding Period (project period): April 2003 – May 28, 2004

Executive Summary

There are many pleasing aspects of the process and the final product. The book looks good, I am very happy with the content, and, in keeping with the original objective, it is user friendly. Comments from those who have already seen the book are enthusiastic.

2,500 copies of 'Kids' Grief: A Handbook for Group Leaders' are now ready for distribution.

The first draft was completed on schedule, but the final product was delayed and a time extension requested and granted.

Reasons for the delay included:

- the author's absence overseas for a previously agreed work commitment
- heavy work commitments of subject experts – delayed clinical review
- design and printing complexities

The project was completed within the agreed extension period.

The project's process included liaison with other children's services nationally and internationally and facilitated development of a valuable network for mutual support and information exchange. Focus groups provided valuable suggestions for additions to content, and for refining the manual presentation to enhance user friendliness.

Overall, the project process has been an enjoyable and fulfilling experience which I hope will flow on to those using the finished product. I intend to design a training course for support group leaders to enhance their ability to use the manual effectively and will convert the course content and process into a Trainers' Manual in 2005.

1. **Objective** (from project plan) – **To increase the capacity of palliative care staff in conducting support groups for dying and bereaved children and their families**

Strategies List the Strategies from your project plan	**Activities/Progress** What progress have you made with your strategies in this reporting period? Did you actually do what you planned to do during this six-month period (as specified in your project plan)? If not, what did you do that you had not planned on? If not, what did you not do that you had planned to do? For each variation from the original plan, please explain why.	**Outcomes/deliverables** Did you actually produce during this six-month period what you planned to produce? eg reports, education packages, questionnaires, information pamphlets, and reference committee. If not, what did you produce that you had not planned on? If not, what did you not produce that you planned to produce? For each variation from the original plan, please explain why.	**Timeframes in which strategies were achieved**
1. Development of Manual Content	Research and investigation of materials used over the years and ascertain which is most relevant to the manual. Development of bereavement program/framework for inclusion in handbook Testing of content with support groups for bereaved kids from 9-10 years	• Researched & collated relevant material • Developed sample programs * Refined exercises for inclusion in program	May – December 2003
2. Trial and modification of Manual Content	Focus groups with palliative care workers and others Facilitation of feedback from Focus groups Incorporation of feedback from Focus groups	• Liaison with other services • Development & facilitation of focus group programs • Collation & summary of focus group Feedback * Incorporation of feedback in manual	December 2003 – March 2004

2. Objective (from project plan) – **To increase availability of counselling and support resources for bereaved and dying children and their families**

Strategies List the Strategies from your project plan	**Activities/Progress** What progress have you made with your strategies in this reporting period? Did you actually do what you planned to do during this six-month period (as specified in your project plan)? If not, what did you do that you had not planned on? If not, what did you not do that you had planned to do? For each variation from the original plan, please explain why.	**Outcomes/deliverables** Did you actually produce during this six-month period what you planned to produce? eg reports, education packages, questionnaires, information pamphlets, reference committee. If not, what did you produce that you had not planned on? If not, what did you not produce that you planned to produce? For each variation from the original plan, please explain why.	**Timeframes in which strategies were achieved**
3. Production of Manual	Liaising with printers, editing drafts of manual etc	Completed as planned + consults with Artist to develop cover design	March 2004 – May 2004
4. Marketing and dissemination of manual	Development of marketing and sales strategies Promotion of manual at conferences, in media etc	Liaison with web site designer to develop Promotional material and on-line purchase facilities * develop a promotional flier	May 2004 – June 2004 * conference promotional opportunities not available until July, August & September

3. Objective (from project plan) – **Sustainability of Manual and ongoing support; improved scope of support**

Strategies List the Strategies from your project plan	**Activities/Progress** What progress have you made with your strategies in this reporting period? Did you actually do what you planned to do during this six-month period (as specified in your project plan)? If not, what did you do that you had not planned on? If not, what did you not do that you had planned to do? For each variation from the original plan, please explain why.	**Outcomes/deliverables** Did you actually produce during this six-month period what you planned to produce? eg reports, education packages, questionnaires, information pamphlets, reference committee. If not, what did you produce that you had not planned on? If not, what did you not produce that you planned to produce? For each variation from the original plan, please explain why.	**Timeframes in which strategies were achieved**
5. Planning for ongoing sustainability of manual	Development and promotion of email and on-line support for purchasers of manual Ongoing marketing of Manual to fund its continued availability	• development of locked section of web site, available to those purchasing manual for support, advice question/answer section • promotion at all BCC workshops in Aust. & New Zealand • Promotional material to be sent to sister centres nationally and internationally & linked to all Appropriate web sites	June 2004 – July 2004

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Evaluation Activities

Activity What evaluation activities have you undertaken in the last six months? Eg Surveys/questionnaires, focus groups, interviews. Please identify the tools you used, ie from the CCP toolkit, or please attach any instruments you developed yourself. If you undertook more than 4 evaluation activities in this period, please append an additional page	**Results** Briefly describe the results of each activity, being as specific as possible. Wherever possible, please report your results in both quantitative and qualitative terms. Eg 15 survey forms on community awareness of palliative care completed. Key results were: - 12 respondents had little or no awareness of palliative care; - Women had a better knowledge of palliative care than men, with 6 out 8 reporting that they had good knowledge and 1 of 4 men reporting good knowledge; - 8 out of 15 respondents thought that palliative care services in this community could be improved by the provision of home based care.
Activity 1: Focus group 2 – Albury – Feb 2004	Tools used – same as for focus group 1 (summary of outcome sent snail mail)
Activity 2: Content review – subject experts – March 2004 – April 2004	No significant changes necessary. Some changes to wording Some simplification of exercises
Activity 3: Development of manual feedback form	Copy sent by mail. To be returned to author by purchasers After trial use of manual
Activity 4:	

Please note: sustainability, generalisability and capacity building checklists should be completed by all projects during the first six-month period

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Dissemination Activities

Activity What dissemination activities have you undertaken in the last six months? If you undertook more than 4 dissemination activities in this period, please append an additional page	**Results**
Activity 1: Liaison with colleagues nationally & internationally	Enthusiastic response – desire to purchase & willingness to promote. Invitations to present at conferences nationally & internationally
Activity 2: Development of mailing list	E-mail and snail mail lists ready to use for promotion as soon as book is released
Activity 3: Development of web site	childhoodgrief.com.au
Activity 4 Development of promotional flier	Currently awaiting Board approval and funds for printing & mailing

Dissemination activities include:
(1) Presentation or talk to staff at one service or agency in the local area (eg, talk at a staff meeting, during a hospital grand round); (2) Talk to staff from more than one service or agency in the local area (eg, talk at an interagency meeting), (3) Story in the local newspaper (4). Story or article in a local magazine or newsletter (eg, GP news, hospital newsletter, community agency newsletter) (5). Story or article in a professional or industry magazine or newsletter (6). Presentation or poster at a local conference (7). Presentation or poster at a State/Territory conference (8). Presentation or poster at a national conference (9) Peer-reviewed journal article (10). Information provided on a website (11) Any other way you have told people about your project

- **Word of mouth – NCCG counsellors telling people of its development**

- Preliminary notice of availability – shown on Bereavement Care Centre web site www.bereavementcare.com.au

- Advance notice of manual's availability given at BCC workshops throughout Australia and New Zealand – 2003-4

Additional Comments

What have you learnt from these evaluation activities/results? Based on what you have learnt what changes will you make in the next six months?

Learning has mostly been around reinforcing my belief that networking and maintaining active communication links with professionals in the field is an invaluable way in which to enhance knowledge, provide mutual support, and extend the nature of services offered to palliative care patients and their families. My belief is that community based services will not expand or survive without these links and that hospital based services would continue, from necessity, to focus on the immediate physical needs of patients in their care.

My belief in the need for, and value of, well-trained volunteers to work alongside paid professionals, has also been reinforced. There are many competent, professionally trained people in the community not wishing to work full time, who, with the support of resources such as this manual, training courses and clinical supervision, could help to creatively expand the nature and amount of care that palliative care services provide in hospital and community settings.

I learnt most from the role-plays I designed for each focus group. In these role plays I was able to observe teams composed of a mixture of volunteers and paid professionals as they grappled with practical difficulties involved in providing group support for the families of dying patients, and those who were already bereaved. Formal feedback was also useful, but did not have the same degree of spontaneity or the dramatic impact of the role-plays.

Most of the refinement of the manual content and presentation came from this process. I think, overall, the importance of ongoing support, easy access to a trusted subject expert to answer practical questions and provide encouragement, was highlighted as a widespread need. For this reason, I have been encouraged to focus my attention for the next 12 months on developing e-mail access and support as one way of addressing this need.