Final grant report: Knowledge of and attitudes towards the legal rights of gay, lesbian, bisexual and transgender people for appropriate end-of-life care

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<th>Project title</th>
<th>Knowledge of and attitudes towards the legal rights of gay, lesbian, bisexual and transgender people for appropriate end of life care</th>
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<td>Grant recipient</td>
<td>Aged Services Learning and Research Centre</td>
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<tr>
<td>Project manager</td>
<td>Professor Colleen Cartwright</td>
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<td>Position</td>
<td>Director, ASLaRC Aged Services Unit</td>
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<td>Law and Justice Foundation awarded amount</td>
<td>$35,590.91</td>
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<td>Grant period</td>
<td>March 2010 – January 2012</td>
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<td>December 2011</td>
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Description of the project

Describe the project in just enough detail so that anyone can understand the aim of the project, the target group and what strategies were undertaken to achieve the aim.

This project sought to: (a) investigate what gay, lesbian, bisexual, transgender and intersex people (GLBTI) in NSW, and their service providers, know about their legal rights in relation to appropriate end-of-life care, and what their attitudes are to these issues; and (b) to develop resources which would inform and educate GLBTI people and the service providers to undertake Advance Care Planning for the end stage of life, and to empower them to be advocates to ensure that their legal rights were respected.

The project – what happened?

How did the project come about?

A study conducted by research staff of the ASLaRC Aged Services Unit of Southern Cross University in the Northern Rivers region of NSW in 2009, which investigated end-of-life care issues for GLBTI people, found evidence of active discrimination and abuse of GLBT people at the end of life (Lienert, Cartwright, Beck, Phase 1 Report, 2010). To gauge the extent of this issue, the research team applied for, and received, funding from the NSW Law and Justice Foundation to conduct a State-wide survey of GLBTI people and service providers, and to use the findings of that survey to develop GLBTI-specific end-of-life care planning resources.
Briefly set out the project stages and what happened in each stage.

The project was conducted in 2 stages:

Stage 1 involved a state-wide, hard copy and on-line survey, distributed through GLBTI organisations and mailing lists. Responses were received from 306 individuals; analysis of the surveys demonstrated that there was limited understanding of the legal options available to GLBTI people to ensure that their end-of-life care wishes were respected, and that many had experienced direct discrimination from health care providers, and/or the families of their terminally ill partners. A full report of the findings of Stage 1 can be found on the ASLaRC website: (http://aslarc.scu.edu.au, go to Downloads and scroll down to Publications and Reports: Cartwright, Lienert, Beck, Phase 2 Report, 2010).

In Stage 2, a GLBTI- specific Resource Booklet and Advance Health Care Directive were developed and distributed to GLBTI organisations and other relevant stakeholders. These resources are also available for free download from the website above.

If grant materials were produced:

How were they distributed?
The resources resulting from the project were distributed to the Law and Justice Foundation, to the members of the project Steering Committee, most of whom represented GLBTI support organisations and community legal centres, and to attendees at the launch of the Resource Booklet and GLBTI-specific Advance Directive. In addition, they were made available on the ASLaRC website and on the websites of Steering Committee members’ organisations and other related websites.

What was the extent of the distribution?
As with the distribution of the questionnaire, it was not possible to know how widely the resources have been distributed, or have been accessed from the various websites. ASLaRC has distributed approximately 50 copies of each, at the launch, at relevant conferences and to people who participated in the project and requested a copy; Steering Committee members also confirmed that they have distributed them widely.

What has been the extent of online use (if applicable), at the time of this report?
As above: the ASLaRC website is accessed many times per week – and sometimes per day - and while we have a “counter” which can record the number of “hits” per day, it is not possible to know which documents are being accessed each time.

Now that the project has concluded, how did the implementation and/or the outcome differ from what was originally intended?
The project suffered a setback when one of the key members of the Steering Committee – previously the Project Coordinator – was tragically killed in a car accident a few months before the conclusion of the project. As she was one of the most active members of the Steering Committee, and also had the strongest GLBTI networks, her death not only caused shock and grief among the research team and Steering Committee members but also affected dissemination of the resources. The Project Manager (Prof Cartwright) was able to access her materials relating to the project, and therefore recover the situation, but the impact on all was significant. The only positive to come from this was that we were able to see, first hand, how knowledge and resources can empower GLBTI people – and indeed, all community members – at such a challenging time. The woman who was killed and her partner had
appointed each other as Enduring Guardians and had also both completed an Advance Directive; this enabled the partner to “negotiate” the health care system, and to interact with the woman’s family while retaining her rights in relation to required decisions, including those relating to life-sustaining measures.

Despite the above, the project met its objectives and we believe that the resources produced will be of great benefit to GLBTI people and their service providers.

**Evaluation**

**What questions did you ask to evaluate whether you had achieved your aim?**

In **Stage 1** only 1 evaluation question was asked and that was “Did you find the survey helpful?”

For **Stage 2**, a 2-page anonymous questionnaire was distributed to 32 recipients of the Resource Booklet and GLBTI-specific Advance Health Care Directive: Page 1 asked respondents to rate their level of agreement, on a 5-point Likert Scale, from Strongly Agree to Strongly Disagree, to a series of statements about the Booklet itself (see next section for questions asked and responses), Page 2 asked respondents: (a) if they were GLBTI individuals, service providers, both or neither; (b) their age; (c) if they preferred to access the Booklet in hard copy, on line or both; and (d) whether there were other issues affecting GLBTI people that they would like more information about.

**What data was gathered?**

**Stage 1:** A total of 291/306 respondents answered the question about how helpful the survey was; of these 32% said that it was Very Helpful; 53% said Helpful (i.e. 85% said Helpful or Very helpful); 9% said that it was Not Applicable as they already knew about the issues in the survey; and 6% said that it was Not Helpful.

**Stage 2:** Twelve respondents returned the evaluation questionnaire (38%)

- 100% of respondents strongly agreed or agreed that they found the Resource Booklet easy to read in relation to print size; 91% did so for both layout and language level;
- 100% of respondents strongly agreed or agreed that the Booklet covers the most important issues that need decisions at the end of life;
- 59% of respondents strongly agreed (16%) or agreed (43%) that after reading the Booklet they know more about their end-of-life rights (or the rights of people they provide service services to) than they did before; 25% neither agreed nor disagreed and 16% disagreed (they wrote on the questionnaire that they already had a lot of knowledge about the topic).
- Only 33% of respondents agreed (and none strongly agreed) that the Booklet did not tell them anything they didn’t know, while 25% were neutral and 42% disagreed with this statement (i.e. at least 42% of respondents learned something(s) new from the Booklet;
- Only one respondent (8%) strongly agreed (and none agreed) that, as a result of reading the Booklet they had taken action on end-of-life planning for themselves, but this may...
have been because the time between receiving the Booklet and receiving the evaluation questionnaire had been too short for them to do so.

- This assumption is supported by the fact that 66% of respondents said that, as a result of reading the Booklet they intend to take action on end-of-life planning for themselves; and

- 92% strongly agreed/agreed that having read the Booklet, they know where to access further information, advice and assistance on end-of-life care planning; one (8%) gave a neutral response.

- While 68% of respondents strongly agreed, and 16% agreed, that the Booklet should be provided to all medical, nursing and law students in NSW, 16% disagreed with this statement, which was somewhat surprising. However, as these were anonymous questionnaires it was not possible to “go beneath” those response to understand why this was so.

- Despite the reservations of some respondents to the above statement, 100% of respondents strongly agreed (67%) or agreed (33%) that the Booklet should be provided to all doctors, nurses and solicitors in NSW.

- 100% of respondents strongly agreed (84%) or agreed (16%) that they will refer others to the Booklet and 49% said that they had already done so.

- Finally, 100% of respondents strongly agreed (75%) or agreed (25%) that they would recommend the Booklet to GLBTI friends/clients/service providers.

Other questions/responses:

- Of the 12 respondents who returned their questionnaires, (a) 2 identified as a GLBTI individual; (b) 4 as a service provider to the GLBTI community, 4 as both (a) and (b), and 2 as neither (a) nor (b).

- Age range of respondents was: 3 were aged 40-49 years; 5 were aged 50-59 years; and 4 were aged 60-69 years. (This was interesting as we are aware that some of those to whom the questionnaire was sent were younger than 40 years). It suggests that perhaps they do not see the issue as quite so relevant to them yet.

- The majority of respondents (68%; n=8) said that they equally preferred to access the Booklet in hard copy and on-line; 16% (n=2) in each case nominated hard copy and on-line as their preferred method of access.

Chi-sq analysis of all of the responses to the above questions was undertaken but, given the small number of respondents and the similarity of responses, the results were not meaningful.

Respondents were invited to add comments at the end of their questionnaire. Only one person did so, but the comments confirm the value of the project and the resources:

“The as a GLBTI individual who found myself recently in the tragic situation of having to make end-of-life care decisions for my partner, I couldn’t thank her enough for having insisted years ago that we had all documentation in place. This was of no end of comfort to me, to know my partner had given me authority as her legal guardian when dealing with difficult
family members and hospital social workers with a lack of awareness about problems GLBTI couples face when dealing with the hospital system.

I was equally alarmed at the time to learn how many GLBTI couples in my immediate circle, including those with children, did not have wills or Power of Attorney docs drawn up. I hope this booklet helps to stir this complacency and more members of our community to act. It is a wonderful resource with good, practical information. I could not state enough how different my experience of caring for my dying partner would have been if we did not have these important docs within reach.

The more training which could be given to all workers in the health system for dealing with GLBTI patients and couples the better. The booklet is a great resource and a good start. Thank you.”

**Did you achieve your aim? What did you find out?**
The project achieved its aims in both areas:

(1) The report of the state-wide survey provided clear evidence of areas where there was very poor (or non-existent) knowledge of the law in relation to end-of-life care planning and rights of GLBTI people. This allowed the development of very specific resources to address the identified needs;

(2) The very positive responses of those who evaluated the Resource Booklet indicate that it is appropriate to address the gap in knowledge (and, potentially, attitudes) in end-of-life care/care planning for GLBTI people and their service providers.

**Conclusion and recommendations**

**What is your conclusion?**
Access to existing legal options for end-of-life care-planning is negatively affected by lack of knowledge among many members of the GLBTI community and their service providers about these options. Attitudes of health care providers in the wider community constitute an additional barrier for GLBTI people to access their legal rights.

Wider dissemination of the GLBTi-specific resources developed for this project should go some way towards addressing both of these obstacles.

**What are your recommendations for improvements both for the intended audience of your project, and for the strategy you used to achieve your aim?**

**Recommendation 1:**
That focussed education about legally available Advance Care Planning options for GLBTI people and their carers be made available through the organisations that currently work with this community (e.g. ACON and The Gender Centre), via Newsletters and Magazines; in addition, such education should be included in the planned on-line resources being developed by the Office of the NSW Trustee & Guardian and others;
Recommendation 2:
That education about the legal rights of GLBTI people in relation to Advance Care Planning, authorised substitute decision-makers (even in the absence of ACP) and other end-of-life decision-making issues for GLBTI people be included in the curriculum of doctors, nurses, lawyers, social workers and pastoral care workers in the health and legal systems.

Recommendation 3:
That GLBT organisations and NSW Health work with the Divisions of General Practice (now called GP Networks) to encourage GPs to become familiar with the law in NSW relating to Advance Care Planning and to discuss these issues with their GLBT patients (as well as with patients generally).