

Senator Rachel Siewart

Michele Wiese

Chair Palliative Care Inquiry

Senate Community Affairs References Committee

Parliament of Australia

Parliament House

CANBERRA ACT 2600

23rd March, 2012.

Dear Senator Siewart.

I am a final year PhD candidate at the University of Sydney, examining the palliative care needs of people with an intellectual disability in NSW. I have had nearly thirty years professional experience as a psychologist in the intellectual disability sector.

I request that the committee includes an examination of the needs of ageing people with an intellectual disability who require end-of-life care. In addition to the needs of the broader population, those with intellectual disability have some particular issues that require consideration.

With better health care, access to social support services, and de-institutionalisation, people with intellectual disability are living longer and are outliving their ageing parents, who formerly provided life-long care. Thus, there is increasing pressure on professional community accommodation services to provide ongoing care to these people, and these accommodation services are now, for the first time, providing end-of-life care. With the ageing population, it is expected that this need will continue. My doctoral studies focused on how these community accommodation services currently experience end-of-life care, their needs, and the future requirements of such care. The findings were that staff in community accommodation agencies are:

- Totally committed to providing end-of-life care to people with intellectual disability.
- They cannot do this without support from community palliative care services.
- They have received little, if any, training in providing quality end-of-life care.
- They have variable experience with the "hands-on" requirements of end-of life care.
- They receive variable support from community palliative care services.
- They report that palliative care services, while supportive of providing palliative care to people with intellectual disability in their community accommodation services, feel ill-equipped to address the particular needs of those with intellectual disability.
- Have on occasion, received very poor services from medical personnel in hospitals, and have themselves had to be present at the hospital to care for their client with intellectual disability.
- Well able to provide quality end-of-life care when there has been adequate support from palliative care services.
- Have the support of their client's families to provide intellectual disability; that is, it is everyone's preference.

- Recognise that their client may, due to particular medical needs, have to move to hospital to die, but feel they would be well able to provide care up to that point, given adequate support.

To provide end-of-life care at home, community accommodation staff need:

- Adequate support to palliative care services, provided in the home.
- Training in the “hands on” requirements of end-of-life care.

I welcome the opportunity to provide further information to the inquiry if required. I feel very strongly about this issue. The focus on the palliative care needs of people with intellectual disability as they age is critical, and my doctoral findings are new on the international research scene. I am gratified that there is an inquiry in to palliative care in this country, and thank you for receiving my submission.

Yours faithfully,

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