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Legal and Social Issues Committee
Inquiry into End of Life Choices
Parliament House, Spring St
EAST MELBOURNE VIC 3002

July 30, 2015

Submission concerning end of life choices for residents of disability accommodation services

We would like to bring to the Inquiry's attention the current constraints upon end of life choices available to Victorians who live with severe disability, particularly intellectual disability.

Over the past two years we have been involved in a study of end of life care in residential disability homes, drawing upon information and insights emerging from the appointments, as part of a Victorian Department of Health project, of disability palliative care workers in each health region of Victoria. These workers have been located in community palliative care services and have collaborated in a variety of ways with disability accommodation services (including the Department's DAS) in their regions. Their brief has been to introduce a palliative approach, based on the palliative approach used in aged care, to residential disability services.

While the idea appears straightforward in principle, in practice it has proved much more complex. For example, regulations that require mainstream services to deliver healthcare to residents of disability services regularly see residents transported to hospitals which have neither the time nor expertise to meet their everyday communication and care needs. This is difficult enough when illness is episodic, but it makes dying 'in place' (if this is a resident's wish) very difficult indeed. Treatment in mainstream services distances residents from the disability staff who are their advocates and primary support people. Treatment and physical care become separated from emotional care and support.

On the other hand, while community palliative care services are tasked to provide care in a resident's home, a different set of problems emerges. While the accommodation is, to all intents and purposes, a resident's home, tasks undertaken by family members in everyday homecare settings cannot readily become part of staff members' care for their residents. To name but a few constraints, administering medication raises a plethora of problems, while processes mandated for serious health events makes dying in their own bed difficult to achieve. Similarly the need to summon police and coroner's officers immediately following a death in disability residential care disrupts the initial hours of mourning for co-residents and staff members. Nevertheless, in our work with DAS staff members we have found willingness to care for dying residents. In our view DAS staff members' familiarity with their residents and skill in communicating with them is an invaluable, in fact indispensable, factor in eliciting and implementing residents' choices about end of life care. But current procedures make providing genuine choice much more difficult than it is for other citizens.

Colleagues in New South Wales are in the final stages of producing Advance Care Planning materials appropriate for residents. This will be an important tool for eliciting end of life care choices of residents in disability accommodation services. But the availability of such materials does not alter the fact that many choices expressed by residents may not be achievable because of constraints imposed by the operating procedures of the various agencies involved.

None of these obstacles is insurmountable, but all of them require a careful review of policy and procedures, as well as alignment between intersecting, and at times dissonant, disability and healthcare policies. Hopefully the recent reintegration of the departments and health and human services will attend to major structural aspects of this. Our work has focused upon regional structural issues, and we have developed a public health approach, based in partnership between disability accommodation and community palliative care services, that has the capacity to review and reform practice. A copy of this strategy document is attached.

We are implementing a trial of this approach in the North West Region of the state, and hope to demonstrate its effectiveness in developing end of life care policies and practice in participating disability residential services. More broadly, we believe that the approach is applicable to a range of groups who are marginalised within society or who have not been able to access palliative care in its current form. We welcome the foreshadowed move to develop a comprehensive end of life care framework, and hope that our work can contribute to extending palliative care insights into areas where current palliative care methodologies do not readily apply.

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PUBLIC HEALTH APPROACHES TO END OF LIFE CARE IN THE DISABILITY SECTOR

The Palliative Care Unit at La Trobe University focuses upon public health approaches to end of life care. This is the first of a series of frameworks provided as a resource to practitioners who wish to introduce a health promoting approach to end of life care in their specific sector.

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People with intellectual disability (ID) are among the most excluded and disadvantaged groups in society (WHO, 2011). Their marginalisation extends to end of life care. People with ID are ageing and are living longer with age-related chronic illness than in the past; but age-related illnesses appear on average 10-20 years earlier than in the general population (WHO, 2011). Residential disability services are about to experience a rising death rate among their residents; but policy and strategies to address this are largely lacking.

A public health approach recognises that many of the health issues experienced by people with disability are due to social factors rather than the consequence of the disability itself (Emerson et al., 2011). These socially determined health problems stem from inequities in the health and social realms and from individual and collective discrimination. A public health approach to end of life care for people with ID is thus particularly concerned with barriers preventing people with ID from experiencing a good death, understood as having choice about place and mode of care. A multi-faceted approach as provided by Health Promoting Palliative Care (HPPC) approach is required to address the range of issues involved. Health Promoting Palliative Care aims to promote death and grief as a normal part of life and to reduce disenfranchised dying, through actions that challenge social norms, support healthy planning for end of life, reduce fears and stigma and build resilience in the face of grief and loss. Drawing upon the core values and strategies of health promotion, HPPC provides a framework that assists practitioners to *enable, mediate and advocate* for disadvantaged or marginalised populations on end of life issues *(see PCU Disability HPPC Framework over page).*

To advance and support HPPC work in the disability sector the Palliative Care Unit has developed two key strategies: 1) an organisational and community capacity building approach building on the disability sector's knowledge and expertise in caring for and supporting their residents with profound disability and 2) a partnership approach to coordinating care with health and other services in response to the wide-ranging needs of people with ID, and those of the staff, family and others who support them in their daily lives.

Our contention is that disability residential services, with their familiar (home-like) environment and their intimate understanding of individuals' physical, emotional and communication needs, are ideally suited to provide end of life support to people with ID *if they have adequate resources, structures and assistance to do so*. Providing palliative care within disability services does, however, raise complex issues for both practice and policies, particularly in coordinating the support required from other health and community services. A people-centred public health approach makes it a priority to provide tailored, in-home medical, nursing and allied health support for residents so that they can receive the high level of individual support they need in their end of life care.

It is imperative that end of life services in disability residential services take account of specific care issues such as communication barriers, treatment in the context of profound disability, symptom management, and staff and family support. Education that increases staff members' capacity to provide end of life planning and support, alongside the development of organisational policy and protocols to guide practical implementation, can lead to sustainable change.

References:

Kellehear, A. (1999). *Health Promoting Palliative Care*. Oxford University Press, Melbourne.
Kellehear, A. (2005). *Compassionate Cities: Public health approaches to end of life care.* Routledge, London.
Emerson, E., Madden, R., Graham, H., Llewellyn, G., Hatton, C. & Robertson, J. (2011). 'The health of disabled people and the social determinants of health', *Public Health*, vol. 125, no. 3, pp. 145–7.
World Health Organization, The World Bank (2011). *World Report on Disability*. WHO Press, Geneva.

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Disability Health Promoting Palliative Care (HPPC) Framework: La Trobe University Palliative Care Unit

Aim: *To build resilience in the Victorian disability sector, its partners and the wider community when encountering issues related to dying, death, loss & bereavement*
Strategy: *Public Health approaches that develop policy and programs **and** build organisational & community capacity in the disability sector so that people living in residential services with a life-threatening illness are cared for appropriately and die in their place of choice*

The La Trobe University Palliative Care Unit (LTUPCU) aims to build capacity in the disability sector in relation to issues of dying, death, loss & bereavement through a Health Promotion Palliative Care (HPPC) Framework that incorporates a sustainable public health approach reflecting a social determinants understanding. It sets out to promote death and grief as a normal part of life through actions that challenge social norms, support healthy end of life planning, reduce fears and stigma and build resilience in the face of grief and loss. The Unit adopts an asset-based approach to guide the work, and uses capacity building principles, organisational and community development methods, advocacy and community participation which recognise that lasting change engages the community you are trying to support from the outset.

Reorient organisations	Develop skills	Strengthen action & advocacy	Create supportive environments	Health in All Policies (HiAP)
Partner with palliative care services to review models of service provision. Services identify people with intellectual disability (PWID) as members of a vulnerable population with particular end of life needs to be considered in assessment & service provision. **Policy, protocols & processes reflect this in service delivery**	**Deliver education & skill development in social approaches to end of life support for disability services staff & caregivers.** Develop staff skills that provide social, emotional and spiritual support to PWID living with a life-limiting illness (LLI) in residential services. **Reduce experiences of marginalised dying**	**Advocate for funding models and resources that support residents to receive end-of-life care in their home.** Undertake cost benefit analysis of care provision in disability residential services compared with care provided in hospitals or palliative care units **Map palliative care service provision & disability sector costs. LTUPCU Project**	**Work with organisations affiliated with disability services regarding end-of-life provision for residents and staff.** Standard practices of the coroner's office, Victoria Police, funeral services, and day programs can undermine good end-of-life care practice for residents, co-residents, staff and families. **Partnership Development**	**Combat death-denying health policies and attitudes that create barriers to dying well.** Organisational policies and practices that view dying solely a medical event, not as a social event, result in inadequate end-of-life support for residents living in supported accommodation. **Build healthy public end-of-life policy**
Partner with the disability sector to build sustainable organisational capacity that support residents with end-of-life care needs. Guide the development & implementation of HPPC practices & protocols to support the sector to incorporate end of life support in service delivery. **LTUPCU Consultancy & Research Projects**	**Promote supported end of life decision making for residents** through the implementing Advance Care Planning processes suitable for people with mild or profound intellectual disability. Deliver training for staff in end of life planning & communication on death & dying. **Deliver training for staff in end of life planning**	**Promote and advocate for the disability sector to take leadership in coordinating end of life care for their residents.** Support & empower services to care for their residents using a social model of dying. **Strengthen health services role in identifying deterioration early.** **Community Development model for sustainable change**	**Develop programs that provide concrete experiences for residents with intellectual disabilities to understand dying and death.** Partnered programs with community organisations such as the arts, or local churches can assist PWID to understand the concept of death. **Practical & concrete programs support PWID to understand the concept of death & dying**	**Create workplace bereavement policies to normalise and promote support for bereaved staff members, family and co-residents.** Bereavement policies work to reduce social isolation in grief, promote healthy workplaces, improve staff and resident support and reduce stress & absenteeism. **Specialised bereavement support for PWID (e.g. sign language)**
Engage community organisations, services & community groups to increase resources for end-of-life support, including local government programs, acute sector, community hospital programs, GP's, community health and volunteers. **Work with existing programs to incorporate end-of-life support in disability services**	**Identify community leaders or volunteers interested in end-of-life support for PWID.** Build capabilities & skills in local volunteer programs to mobilise a **volunteer or pastoral care workforce** that has specific skills to support residents, staff and families in disability residential services. **LTUPCU Project**	Promote **storytelling and legacy** as important healing processes in bereavement. **Develop creative arts projects** that provide opportunities for PWID to participate in rituals of legacy and remembrance, and other creative practices that support healthy bereavement processes. **Concrete activities are helpful for PWID**	**Work with the sector to shift the focus of care from self-determination and independence to quality of life care for the ageing population living in disability residential services.** Early identification of deterioration in the aging residents will improve end-of-life support and care. **Embed Palliative Approach**	How do vulnerable and marginalised groups in our community experience end-of life? **Address access inequities to acute and community health services that provide end of life support.** Services develop policies and protocols that provide responsive and appropriate care to PWID. **End-of-life services map & actively engage vulnerable populations in their region**