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Victorian Government
Victorian State Disability Plan
Department of Health and Human Services
1 Treasury Place, Melbourne, 3000

July 6, 2016

Submission concerning end-of-life choices for people with intellectual disability living in residential services

We would like to bring to the state government's attention the current constraints upon end-of-life choices available to Victorians who live with severe disability, particularly intellectual disability. We would also like to bring to the government's attention a strategy we have developed, based on international standards of care, for an end-of-life framework for people with intellectual disability that specifically addresses two principal concerns of the Victorian state disability plan 2017-2020: namely [2.1] Inaccessible environments, structures, systems and services, and [2.3] Having more say about their lives and the matters that are important to them. We believe this strategy can be effective in addressing the constraints identified below.

Over the past three years, in partnership with departmental disability residential services in Victoria (NEMA), we have conducted research into the feasibility of providing end-of-life care for residents wishing to receive palliative care in their accommodation service. Our work has examined policy, organisation and practice within both the disability and palliative care sectors.

While the idea of supporting residents to die in their place of choice 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, when community palliative care services are tasked to provide care in a residential service, 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 requirement that police and coroner's officers must be summoned 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 disability support workers we have found willingness to care for dying residents. In our view, disability support workers' 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.

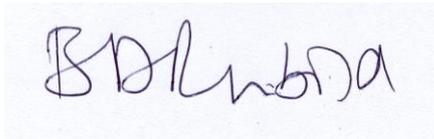
Colleagues in New South Wales and in Geelong are in the final stages of producing training materials and decision-making aides appropriate for residents. This will be an important tool for eliciting end-of-life care choices of residents in disability accommodation services. But the availability of such 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. The transition to the NDIS will introduce further issues to be negotiated.

We are in fact continuing to address these concerns in a working group set up by the North East Primary Care Partnership. Members of the group are drawn from disability and palliative care sectors, and include representatives of DHHS DAS (policy, managers and support workers), the Centre for Development Disability Health (CDDH) Victoria, community health, and researchers from La Trobe University Palliative Care Unit (LTUPCU). The aim of the group is to provide leadership, resources and advocacy for Victorians living with intellectual and developmental disability at the end of their life.

The 'implementation strategy' referred to at the beginning of this submission was developed in the first place for disability palliative care workers in each health region of Victoria, These workers have been funded as part of a Victorian Department of Health project to work with DAS and other disability accommodation services.

The focus of the strategy is upon mobilising the assets that already exist within disability residential services, in particular the practice knowledge and caring skills of the staff, and building end of life care capacity upon them. In addition to supporting disability palliative care workers in their regions, some specific services in the North West Region of the state are involved in implementing the strategy.

We hope to demonstrate the effectiveness of this approach for developing end-of-life care policies and practice in the participating disability residential services. A copy of this strategy document, which has been submitted for consideration in developing the Victorian end of life care framework, is attached to this submission.

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A handwritten signature in blue ink, appearing to read 'A Grindrod', on a light yellow background.

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