La Trobe University Palliative Care Unit

CONCEPT PAPER

END OF LIFE CARE FOR VICTORIANS WITH INTELLECTUAL DISABILITY LIVING IN RESIDENTIAL SERVICES

A CONCEPT PAPER PROPOSING AN IMPLEMENTATION STRATEGY FOR THE VICTORIAN DEPARTMENT OF HEALTH AND HUMAN SERVICES (2015)

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This concept paper has been prepared for the consultation phase of the Victorian End of Life Care Framework Policy being undertaken by the Palliative Care Unit in the Department of Health and Human Services (DHHS). The report draws from experiences of the Victorian Palliative Care Consortia disability program, local and international research and practice, and research undertaken by the La Trobe University Palliative Care Unit in Victoria.

Acknowledgments
The idea of developing a concept paper was first put forward in a meeting of the Victorian Palliative Care Consortia (VPCC) Disability Network early in 2015. Theresa Williamson, Acting Head of Department, Palliative Care Unit, Victorian Department of Health and Human Services (DHHS), was in attendance, and discussion began to link the range of initiatives undertaken and challenges experienced across the state in disability palliative care, the previous VPCC Disability Program (2011-2105), and the Department’s decision to develop a new Victorian End of Life Care Framework. Those present agreed on the importance of documenting the insights that had been gathered through the network, and the La Trobe University Palliative Care Unit (LTUPCU) offered to develop a concept paper, with input from VPCC disability program staff. A template was used to collect contributions from the VPCC across the state and those completed were returned to the LTUPCU. In addition to these formal responses, the VPCC Disability Network has met in various forms since the commencement of the previous Victorian policy, and many of the shared discussions that have taken place over those years are drawn upon here. The draft version of this paper was circulated to the VPCC Disability Network and DHHS Disability Accommodation Services (DAS) at state and regional North East Metropolitan Area (NEMA) level for comment.

The authors take responsibility for the content of this paper, and are not claiming that the paper represents the opinions of the VPCC or DHHS DAS as a whole. We hope however that we have reflected accurately policy and practice issues that have been reported from both fields.

We would like to acknowledge the contribution of the Loddon Mallee Palliative Care Consortium (LMRPCC), in particular Kate Cozens and Lisa O’Connor, who agreed to undertake structured consultation with their contacts in the disability sector in the Loddon and Mallee areas (Bendigo and Mildura and surrounding districts) to support the development of this paper. The information gathered by Kate and Lisa contributed valuable insights and solutions generated by the disability sector: many of these have been included in this paper. This collaboration was undertaken as part of a consultancy provided by LTUPCU, and the report can be accessed via Susan Morgan, Manager of the LMRPCC or Andrea Grindrod at LTUPCU.

We would also like to express our appreciation to the North West Metropolitan Region Palliative Care Consortium (NWMRPCC) under managers Tracey Mander and subsequently Michael Gourlay, who funded LTUPCU to conduct a research project (2013 – 2015) on providing end of life care in disability residential services. This project in turn provided opportunities to partner with DHHS Disability Accommodation Services through the North East Metropolitan Area (NEMA) Palliative Care Community of Practice, a connection which has been critical to improving our understanding of the issues in this area. Our gratitude is extended to Maree Belleville, (DAS Manager, NEMA) and Chair of the Palliative Care Community of Practice, who has generously supported collaborative work, enabled applied research and shared her expertise from practice in the field.

And finally, a thank you to Dr Helen Varney, Honorary Associate at the LTU Palliative Care Unit for her generous time and meticulous attention to detail in reviewing various versions of this paper.
# Table of Contents

Acknowledgments .................................................................................................................. 2

Background ............................................................................................................................. 4

Introduction ............................................................................................................................. 4

Analysis of Current Practice in Victoria .................................................................................. 5

Context .................................................................................................................................... 6

Local and International Developments ................................................................................. 7

Understanding and Categorising the Issues ......................................................................... 8
  - Disability Specific issues ..................................................................................................... 9
  - Practical Issues .................................................................................................................. 12
  - Cultural Issues .................................................................................................................. 12
  - Structural Issues ............................................................................................................... 13

A Solution Based Framework (Structural, Cultural, Practical) ............................................. 14
  - Principles Underpinning the Solution Based Framework ............................................... 15

Implementation Strategy ....................................................................................................... 16

Conclusion ............................................................................................................................... 16

Future Directions .................................................................................................................... 17

References ............................................................................................................................... 18

Appendix ................................................................................................................................ 21
  A. Solution Based Matrix ...................................................................................................... 21
  B. Disability End of Life Implementation Strategy ............................................................... 21
  C. The 13 European Norms and a Victorian Implementation Strategy: A Comparison ....... 21
  D. A Public Health Framework for Disability End of Life Care ........................................... 21
Background
This paper describes practical, cultural and structural issues encountered when implementing the disability component of the previous Victorian Palliative Care Policy 2011-2015. It also describes the assets identified both through conducting the Victorian Palliative Care Consortia disability program and collaborative research undertaken by La Trobe University Palliative Care Unit.

We have gathered this evidence to assist the Department of Health and Human Services (DHHS) to address the needs of people with intellectual disability in the forthcoming Victorian End of Life Care Framework 2016.

The aim of this paper is to summarise, analyse and offer an assets-based, solution focused implementation strategy to address end of life issues for people living with an intellectual disability (ID) in residential services in Victoria.

Introduction
People living with an 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). Thus residential disability services are about to experience a rising death rate among their residents as the baby-boomer generation ages; but policy and strategies to address this are largely lacking.

Compared with the general population in Australia, people with ID have poorer health outcomes and higher risk factors (AIHW, 2010), they have more complex health needs (Beange, 1996), and are hospitalised at twice the rate of the general population (Beange, 1996), in part due to the increased barriers to accessing health services (VicHealth, 2012). However, in light of the evidence that many of the health issues experienced by people with disability are due to social and economic disadvantage rather than the consequence of the disability itself (Emerson et al., 2011), it is important to remember that compared to the general population, people with ID have more similarities than differences when it comes to palliative and end of life care needs (Cartlidge & Read, 2010). The underlying principles that guide good end of life care for people in Victoria are the same for those Victorians living with intellectual disability. The challenge is to bring the expertise of both the palliative care and disability sectors together, at state, regional and local levels, to address the differences that result in poor end of life experiences for people with ID, their family and carers. According to the White Paper; Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe, produced by the European Association for Palliative Care (EAPC) Taskforce on People with Intellectual Disabilities (Tuffrey-Wijne et al., 2015), the most important and essential factor in providing opportunity for this population to die well is collaboration between services, particularly palliative care and disability services:
Across Europe, it appears that good practice is often dependent on the commitment of dedicated individuals, rather than on good policies, systems or guidelines. Sometimes, excellence seems to be achieved despite the system, rather than because of it. However, experience from some European countries demonstrates that with sufficient attention to the needs of people with intellectual disability, and with the passion of dedicated staff, change can be achieved within systems, structures, national guidelines and funding streams. Sharing best practice is an important part of that process (Tuffrey-Wijne et al, 2015, p. 4).

Analysis of Current Practice in Victoria
The disability program funded under Strategic Direction 3 in the previous Victorian policy, to ‘improve palliative care capacity in disability accommodation services’ (impact) and ‘[ensure] that people living in disability accommodation services who have a life-threatening illness are supported to be cared for and die in place’ (actions) provided a platform for understanding the complex practical and systemic barriers to achieving this strategy (DHS, 2011). Under this policy, disability workers have initiated a range of activities such as palliative care consultancy services to group homes, education and training for the disability sector on the palliative approach, training for palliative care staff on the disability sector, and formation of a Palliative Care Community of Practice in DHHS Disability Accommodation Services.

However, despite the strong commitment and skilled work of the regional disability staff in undertaking these activities, they continue to meet structural, cultural and practical barriers to their initiatives. That is, despite good intentions, and even with good planning by both palliative care and disability staff, poorly aligned organisational policies, practices and resource constraints in both sectors can interfere with attempts to keep a dying resident at home. This often results in a transfer to hospital where, anecdotally, all too often, he or she dies in the Emergency Department (ED). Cross and colleagues (2012), reporting on practical approaches to improving end of life care for people with intellectual disabilities, showed that whilst palliative care and disability services recognised the need, and were willing to partner, this alone was not enough to ensure care according to the resident’s choice. A lack of collaboration at senior levels in organisations can undermine the effectiveness and sustainability of partnerships at the level of service delivery. Partnerships ‘on the ground’ have implications for organisational policy.

Whilst good outcomes have been achieved for some dying residents through local collaboration, choice at end of life for all people with ID living in residential services has not, and probably cannot, be achieved through local initiatives alone. When a person with an intellectual disability dies well, receiving good end of life care, in a familiar setting with familiar people around them, it’s because a few dedicated staff have managed to negotiate around the structural barriers embedded in service systems, organisational policies and legislation. The increase in workplace stress created by structural barriers when caring for a
resident at end of life (Grindrod & Rumbold, 2015) is one issue, but an increase in workplace related risk for both staff and residents is quite another, and makes a good argument for policy review. As an example, a Clinical Nurse Consultant in a Specialist Palliative Care Service in Tasmania (Coulson, 2015) reported on some risks encountered, but overcome in that instance, including safe drug administration and storage, measures for symptom assessment and breakthrough treatment, equipment needs required for safe care and ‘organisation policy for unwell patients’ (compulsory life-saving policy). Risks for disability support workers occur when end of life care in the group home is not supported by organisational protocol. Under current arrangements the wishes of some dying residents can be met when some staff members contribute beyond the obligations of their roles, and service providers tailor care to the setting. Choice at end of life for all will require infrastructure changes to support healthy end of life experiences for everyone involved.

Despite these structural barriers, however, implementation of the disability program in Victoria has identified the willingness and commitment of many disability support staff to provide end of life care to residents in their ‘home’. This is consistent with research findings at local, national and international levels (Grindrod & Rumbold, 2015; Ryan et al., 2010; Weise et al, 2012). This preparedness of staff members to be involved in end of life care should be considered an important organisational asset to be supported and expanded. It provides a foundation for social dimensions of end of life care to be provided primarily within the disability sector, supported by medical, nursing and other community services as required (Grindrod & Rumbold, 2015). A corresponding asset, a capacity to build on strengths rather than focus on limitations, can be found in people with ID. The EAPC White Paper refers to research that finds people with ID dying from cancer as ‘remarkably’ resilient in the face of declining health and impending death, reportedly attributed to the resilience required to live with disabilities (Tuffrey-Wijne, 2010).

**Context**

The focus of this paper is end of life care for people with intellectual disability living in residential services in Victoria. These services are provided both by the Department of Health and Human Services (DHHS) Disability Accommodation Services (DAS) and non-government organisations, also known as Community Service Organisations (CSOs). Both types of residential services support people with physical and intellectual disabilities, ranging from mild/moderate to profound, and operate within an organisational structure to provide community living experiences for residents. The Victorian Residential Services Practice Manual (RSPM) provides the policy and protocols that set the standards of care to meet legislative requirements for residents in accommodation services and, whilst DHHS DAS is regulated by the manual, the CSOs are guided by the manual. The RSPM includes a section on palliative care, and the Disability Residential Services Palliative Care guide: End-of-life care for residents of disability residential services (DHS, 2009) provides a guide to palliative care, but these resources do not take into account the cultural and structural limitations at the practice
level, nor do they provide the resources required for implementation, such as checklists, practice instructions, end of life communication aids and disability specific Advance Care Planning (ACP) resources.

People with ID living at home with parents or living independently, but supported by community services and packages, were not included in the previous palliative care policy, and therefore are not specifically referred to in this paper. However, systemic challenges to providing good end of life care for people living with an intellectual disability in the community are equally relevant, and many of the good practice principles discussed in this paper should also apply to this group. Further, people with intellectual disability with a CALD background have also not been included in this paper, in part because they are underrepresented in residential services, and may well be part of those living in the community with family. The needs of this population require further investigation.

The role the National Disability Insurance Scheme (NDIS) in end of life care for people with ID living in residential services or at home needs further exploration. Whilst Individual Service Packages (ISPs) are designed to tailor services to meet individual support needs, there seems to be little, if any, information available on how the NDIS might relate to the provision of end of life support and palliative care needs for people with ID in Australia.

There are further challenges. Many people with intellectual disabilities do not access specialist services (if these are available), making this a largely hidden population. This problem is most pronounced for people with mild and moderate intellectual disabilities, whose disabilities may not be recorded or supported (Tuffney-Wijne et al 2015, pp. 18).

Local and International Developments
End of life care for people with ID is an emerging area for enquiry, in response to growing practical need. Work in Australia is proceeding in several locations. In Victoria, in addition to initiatives already outlined from the Palliative Care Consortia’s disability program, a partnership in the Barwon area is developing an ACP resource for people with ID, and the Palliative Care Unit at La Trobe University is conducting research, piloting frameworks for sustainable practice, and developing education resources in partnership with health, primary care partnerships and DAS in the North East Metropolitan Area. In NSW, the Centre for Disability Research and Policy at the University of Sydney is conducting research and developing resources to support conversations on death and dying that will inform decision making for people with ID. Curtin University in Western Australia is analysing the use of palliative care services by people with ID. The possibility of forming a national network to share findings, tools and resources is currently being discussed.

Internationally, work in the European Union (EU) is further progressed. Research and practice, particularly in the UK, is leading the way on end of life issues for people with ID. Expert
researchers in this field and active formal advocacy groups such as Mencap – The voice of learning disability, are driving change at government and practice level. The recent release of the EAPC White Paper (Tuffrey-Wijne et al., 2015) is a significant contribution to the field. The EAPC Taskforce on People with Intellectual Disabilities developed Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe. Using a Delphi consensus method, 12 known experts across Europe developed 13 standards or ‘norms’ of recommended practice in end of life care for people living with ID in all settings of residency (Tuffrey-Wijne et al., 2015). The paper provides a comprehensive report on what is good end of life care for this population. What it does not provide however is how to implement these ‘norms’. Developing a strategy that systematically and efficiently implements sustainable change to meet these standards is the next challenge.

**Understanding and Categorising the Issues**

The issues contributing to end of life concerns for people living with intellectual disability, their family and carers are many. As stated in the introduction, the intention of this paper is to offer a solution-focused framework within an asset based approach, not to document an endless list of problems. However, it is important to understand the nature of these issues, and even more importantly their origins, as this identifies where solution based interventions are needed. As indicated above, many practical problems in end of life care have their origins in ‘upstream’ structural or organisational problems. Simply focusing on what is visible and problematic ‘downstream’ will not, and cannot, resolve problems that are systemic. Good outcomes can be achieved on a case-by-case basis when the ‘system’ is negotiated successfully, but this ultimately consumes more resources, increases risks for both staff and residents, and doesn’t create sustainable solutions.

It may be helpful to think of these issues as contributing to deciding when end of life care in the group home is ‘no longer feasible’. Some challenges to continuing with care can be resolved by extending existing resources that are amenable to change within the current structures. Other challenges however are beyond the remit of disability support workers, for example, when medical reviews are required for breakthrough pain and symptom management, or an additional staff member needs to be rostered to keep a dying resident at home when attending a day program is no longer an option. These challenges are the type that will repeatedly result in residents being transferred to aged care, or transported to hospital, removing them from their social network and vital personal care supports.

We have analysed and categorised the issues to make them easier to understand, connect them with their origins and locate them within a solution-based structure. The four categories we’ve selected are 1) disability specific issues, 2) practical issues, 3) cultural issues and 4) structural issues. *Disability specific issues* refer to the challenges that are uniquely faced by people living with an intellectual disability, *practical issues* describe the practice based obstacles that impede end of life care, *cultural issues* refer to organisational approaches and individual attitudes that are incongruent with providing end of life care, and *structural issues*
include policies, protocols and systems that obstruct the provision of good practice palliative care. The table below outlines key issues within these four categories.

**Disability Specific Issues**

Disability specific issues are challenges or consequences particular to this population. Assuming access to palliative and end of life care is to be available to all Victorians, regardless of their social circumstances, these issues are challenges the system must overcome to service this population adequately. From the perspective of universal access, it’s not people with ID creating the challenges; it’s the shortcomings of our systems to adequately meet their end of life needs. A re-orientation of the sectors involved, with necessary modifications to systems plus the allocation of resources to provide end of life care in the community, is crucial for all disadvantaged Victorians, not just those living with intellectual disability. These changes will improve outcomes for all Victorians, as creating standards for our most vulnerable populations’ sets the benchmark for best practice end of life care for all.

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<thead>
<tr>
<th>Upstream Issue</th>
<th>Downstream Implications</th>
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<tbody>
<tr>
<td>Expertise in communicating with people with ID is required</td>
<td>Communication difficulties create challenges in understanding death and dying, decision making, Advance Care Planning, communicating with co-residents, pain and symptom management and bereavement support. Specific and complex communication needs are best supported by people with expertise and/or those closest to the person. A desire to protect the person from emotional distress has also been identified as a barrier to communication. Communication issues are core to many issues experienced at practice level, and collaboration between disability and palliative care services is essential in providing good end of life care.</td>
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<tr>
<td>Intellectual Capacity and Understanding Death</td>
<td>Understanding health decline, life-limiting illness, death and dying are important for people with ID, as with anyone. Opportunities for people with ID to learn about death are limited (Weise et al., 2012). Concrete learning experiences, time and proficiency in communication skills (e.g., sign language) are crucial in supporting the dying person and co-residents. It should be assumed a person with ID has the capacity to understand death and dying, unless determined otherwise.</td>
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<tr>
<td>Increased Complex Care Needs</td>
<td>People with ID are more likely to have complex care needs due to increased co-morbidities associated with profound disability. Increased coordination and supervision of care may be required. Collaboration between services is crucial in providing the care required at end of life. Hospital staff often request disability support workers to attend to personal care needs during admission, but this contravenes DAS policy.</td>
</tr>
<tr>
<td>Health Care Inequalities</td>
<td>People living with ID experience increased barriers to accessing health care. Given challenges in communicating about symptoms and pain, life-limiting illnesses are frequently detected late in their trajectory, often as residents enter the terminal phase, leaving little time for preparation and support. A review of reportable deaths on the coroner’s website (Southern Metropolitan Region Palliative Care Consortium, 2013) revealed a short timeframe from diagnosis to death, often with diagnoses and eligibility for palliative care coinciding. Diagnostic overshadowing by treating clinical staff is frequently a problem: disability staff report that treating health care practitioners often dismiss staff reports of resident deterioration, further delaying illness detection.</td>
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<tr>
<td>Recognising Deterioration</td>
<td>Transition markers for deterioration are best noticed by regular care staff members who are well positioned to notice subtle and/or behavioural changes indicating potential health issues. It’s well recognised in the palliative care field that early engagement will improve end of life outcomes for people with life-limiting illness. Protocols and processes systemically imbedded to trigger the earlier detection of disease in people with ID needs to be addressed. Including an ‘end of life section’ in mandated health checks for people with disability, such as the yearly Comprehensive Health Assessment Program (CHAP) visit with the resident’s GP, could be one way of embedding systematic assessment and monitoring of deterioration, thereby triggering a Palliative Approach. Including the ‘surprise question’ in CHAP, and engaging disability support staff in assessing deterioration, could facilitate early detection of illness.</td>
</tr>
<tr>
<td>Incidence and Prevalence of Dementia in people with Down Syndrome</td>
<td>The NHS Improving Quality (2015) reports: All people with a learning disability are four times more likely to develop dementia than the general population, irrespective of the cause of their disability. For people with Down’s Syndrome there are particular issues. 80% of people with Down’s syndrome can now expect to live into their 50s. However, along with an increased lifespan comes an increased likelihood of developing dementia, with 55% incidence in those over the age of 60. Alzheimer’s dementia in people with Down’s syndrome has a much earlier average onset age of 54 years and an average course of 5 years from diagnosis to death. Some group homes house only people with Down’s Syndrome, most of whom, and sometimes all, have a diagnosis of Dementia of the</td>
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### Alzheimer’s Type (DAT)

Systems, protocols and training that orientate the house to a Palliative Approach would greatly benefit residents, staff and family. Forward planning that identifies these residents and their houses to implement dementia-friendly policies and planning would be a proactive strategy for end of life care.

### Personal Care Needs

People with ID living in residential services have their daily care and support needs, including their social and emotional needs, provided by formal carers, making them vulnerable to changes in the site of care, where carers are unfamiliar with their needs, preferences and communication style. In other words, their daily dependence on intimate and familiar care needs makes them vulnerable in *other* systems. Further, co-residents are often friends they’ve been living with for decades. Maintaining care within these networks of relationships is crucial to their well-being and mental health. Removing them to places such as hospital or aged care facilities where it’s difficult to meet these personal needs is not consistent with palliative care principles.

### Post Death Care

All deaths in DAS, even expected deaths, are reportable under the Coroner’s Act 2008. By law, the coroner is required to be notified, and the police attend, to collect the deceased resident’s body. Whilst this legislation was created to protect residents from abuse, when death is expected it can create challenges for staff and co-residents. In particular, fear of unknowingly doing something wrong at end of life contributes to some staff members’ reluctance to provide end of life support to residents in group homes. The follow up paperwork and interviews create added stress following a resident’s death. Organisational support and clear information on policy requirements would be helpful for staff providing end of life care.

### Bereavement

Bereavement support for staff and co-residents is important. Relationships in group homes can span decades. Healthy bereavement, in the shape of normal sorrow, should be allowed to play out without too much interference. Involvement in end of life care for both staff and co-residents could promote healthy grief responses. Identification and treatment of complicated grief in people with ID may be very important for their health and well-being. Residents’ experiences with past loss as a consequence of their disability can make them either more resilient, or more vulnerable to prolonged grief. Ongoing assessment and monitoring is crucial, as is the availability of bereavement counsellors with experience in ID, which is largely lacking.
Practical Issues
Practical issues emerge primarily when human and physical resources to provide end of life care in the home are lacking, when staff training is absent or insufficient, and when the policies and protocols of disability and palliative care are incompatible. There are three fundamental issues for which an upstream response will resolve a plethora of downstream issues:

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<tr>
<th>Upstream Issue</th>
<th>Downstream Implications</th>
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<tr>
<td>Providing Clinical Palliative Support in the Group Home</td>
<td>Providing clinical care in the resident’s home is fundamental to dying ‘in place’. A review of legislation and protocols involving both palliative care and disability on 24-hour pain and symptom management, including breakthrough events, is imperative. NFR orders, collaborative palliative management plans and staff education and training for both sectors are essential, as are strategies to address these issues at state, regional and local levels.</td>
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<tr>
<td>Disability Resources for Dying in Place</td>
<td>Disability residential services are designed to promote self-determination and independent living, but an adjustment is required to support ageing and dying. Finding resources to staff the house when a resident needs to stay home for care can be a problem, as is funding an active staff member overnight. Whilst this seems simple and cost effective to resolve, especially when compared with the alternative of hospital admissions, it is a major barrier to end of life care to be provided in the group home.</td>
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<tr>
<td>End of Life Guidelines for People with ID</td>
<td>Palliative care guidelines (2009) have been developed, and palliative care is included in state-wide protocol (RSPM). However, a review of policies and protocols to reflect contemporary end of life practice, and the development of suitable tools and resources (including human) to support policy in practice, have not yet been created. Nor have lines of reporting on specific palliative care issues for this population within the palliative care sector been established.</td>
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Cultural Issues
Cultural issues relate predominantly to barriers based on perception, beliefs or attitudes. These barriers can become practical limitations, as, for example, if staff members avoid work when a resident is dying, creating a staff shortage. Cultural issues are amenable to change within the existing structures of the organisation, but policy changes will reinforce end of life
as core business for disability residential services, and people with ID as mainstream clients for palliative care services.

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<tr>
<td>Organisational Culture</td>
<td>Disability residential services were created to foster independent living and self-determination for residents. Ageing and related complex health needs, including dying, are becoming an issue as residents approach old age. This requires a shift in approach to care, support and planning, including staff planning for and recognising that a palliative approach and end of life care will be necessary. Without this, default emergency response protocols will be implemented rather than a palliative approach that aims to keep residents comfortable and in familiar surroundings with familiar people.</td>
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<td>Staff attitudes</td>
<td>There is a range of staff opinions on providing end of life care in group homes (Grindrod &amp; Rumbold, 2015). In the absence of explicit organisational direction, that penetrates at operational level, opinions of staff can determine practice, and may not be in alignment with organisational positions. Staff members seem to want what’s best for the resident at end of life, but what is perceived as best varies greatly. Some of these perceptions need revision, and organisations need to provide clear expectations and direction for staff.</td>
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<tr>
<td>Risk Management</td>
<td>In both the palliative care and disability sectors avoidance of physical (clinical) risk is prioritised. Emotional, social and spiritual risks need to be factored in lest physical risk alone excludes providing end of life care in the resident’s home.</td>
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<tr>
<td>Social Dimensions of Dying</td>
<td>Dying is seen predominantly as a medical event amongst disability support staff (Grindrod &amp; Rumbold, 2015). This perception naturally excludes non-medically trained people from a role in the dying process. When staff members are coached on the social dimensions of dying, and the crucial role they can play, a shift from fear to empowerment can be evident, accompanied by a willingness to participate in providing end of life support (Grindrod &amp; Rumbold, 2015).</td>
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**Structural Issues**

Structural and policy issues produce problems that recur repeatedly at practice level. They cannot be resolved at this level, and are therefore the most challenging to deal with. Usually, they’re the ‘sticking point’ that instigates deviation from the agreed ‘palliative management
plan’ and they will pose the most risk for the resident and staff, as working outside them provides the best chance of delivering end of life care at home.

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<td>Departmental Collaboration</td>
<td>Collaboration between palliative care and residential disability services on state-wide policies and protocols geared towards providing care in homes will reduce hospital admissions.</td>
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<tr>
<td>Organisational Protocols in Health and Disability</td>
<td>Formal collaboration between disability support services and services providing community end of life support will assist in identifying incongruities contributing to unplanned hospital transfers.</td>
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<tr>
<td>Funding and Resources</td>
<td>Targeted resource allocation based on grounded advice from disability support workers in particular will enable residents to die in place.</td>
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<tr>
<td>Accountability and Reporting</td>
<td>Sector accountability and reporting on providing end of life services to vulnerable populations, including people with ID, will improve understanding and assist evaluation of the effectiveness of new policy implementation. In particular, health services, including palliative care, should map and analyse the needs of the most vulnerable populations in their catchment area, and develop strategies to ensure service access and tailored treatment.</td>
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<tr>
<td>Medical Enduring Power of Attorney</td>
<td>Legally, a person with ID cannot appoint a Medical Enduring POA, and often, for a range of reasons, family are no longer involved. Staff have no decision making rights when it comes to residents, but they are, more times than not, the person who knows them best. This raises a range of ethical and legal issues that have particular relevance when health and end of life care decisions need to be made.</td>
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**A Solution Based Framework (Structural, Cultural, Practical)**

We have developed a solution-focused framework (See Appendix 1) that considers issues according to their type of constraint; structural, cultural and practical. Solutions are also indicated according to the type of constraint. For example, structural issues are best addressed through adjustments to government and organisational policy; cultural issues through education, community development and adjusting social and workplace ‘norms’; and practical issues through grounded protocols that shape work practice and skill development.
A single issue however might require all three approaches to produce effective and sustainable outcomes. Such issues are likely to be complex and multi-faceted problems such as providing adequate in-home medical and nursing care to prevent unnecessary hospital admissions. In principle, if a problem is structural or ‘upstream’ in nature, it will respond best to a structural intervention. That is, identifying the ‘upstream’ causes of downstream problems suggests both the site for, and type of, intervention required. Another issue, for example, such as engaging the family in care, might simply be addressed through training, and incorporating a check box in the palliative management plan (documentation and skill development).

A few well-implemented policies and protocols (existing or new) that are embedded into systems management will solve many issues that surface at a practical level. This approach becomes crucial when daily practical challenges are being resolved by operating at the edges or outside of organisational policy. Despite good work that occurs in particular situations, risk and staff fatigue are increased because existing systems erect barriers that must be overcome. Sound organisational structures, systems and protocols will facilitate practice change more readily, with less energy expended at the operational level. At the same time these will contribute to shifting organisational culture, as staff attitudes and resistance shift in alignment with organisational direction.

A partnership approach within DHHS between palliative care and disability accommodation services will be the foundation for effective strategy to address the structural and policy barriers to providing end of life care in disability residential services. Likewise, partnerships between palliative care and disability services will mobilise organisational cultural shifts, and translate new policies and protocols into practice at the operational level. Education and training for both sectors will address some of the practice and attitudinal issues, but policy and protocol development is essential for sustainable organisational change.

**Principles Underpinning the Solution Based Framework**

Principles central to a public health approach underpin the framework and are fundamental to a sustainable implementation strategy. A public health approach recognises that individuals are part of a system, and that these systems will determine the health and well-being of the most vulnerable within them, as they are the most dependent upon them.

Specifically, in considering people with intellectual disability at end of life, a public health approach aims to build capacity in relation to issues of dying, death, loss and bereavement that reflects 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 (Grindrod & Rumbold, 2015). Building on strengths, an asset-based approach affirms existing capacities and culture, and establishes new structures that support developing solutions. Organisational
and community development methods, including advocacy and community participation, recognise that lasting change engages the community you are trying to support from the outset, and that resource allocation and upstream interventions are best informed by evidence gathered at practice level (Sallnow and Paul 2014; Sallnow et al 2015).

**Implementation Strategy**

We have developed a Disability End of Life Implementation Strategy for consideration in developing the new Victorian End of Life Care Framework (See Appendix 2). The strategy combines the evidence-based consensus norms from the newly released EAPC White Paper and the public health approach to disability and end of life framework developed by La Trobe University Palliative Care Unit. The strategy offers a workable solution to improve end of life outcomes for people with intellectual disability across the state.

The overall implementation design is based on a public health approach to end of life for people with ID (Grindrod & Rumbold, 2015), but includes within it the 13 Consensus Norms developed by the EAPC (Tuffrey-Wijne et al., 2015). The key concept behind the implementation strategy is the assigning of the consensus norms (and other identified areas in health promotion approaches) to sectors based on expertise, thereby creating areas of accountability. Whilst collaboration is essential across all areas of end of life care, successful implementation and sustainability are improved if each sector is designated as the ‘lead’ in areas that match its expertise. For example, as outlined in the public health framework, the disability sector has the skills and expertise to lead on the social dimensions of end of life care for people with intellectual disability, and the palliative care sector on the medical and nursing aspects of care. Both are critical to achieving optimal outcomes for the resident, affirming the significance of collaboration. By identifying accountable roles of lead responsibility and areas of equal partnership between sectors and services, the total needs of the resident at end of life are less likely to be overlooked.

A schematic overview of the proposed implementation strategy has been developed to illustrate the strategy and is found in Appendix 2 following.

**Conclusion**

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 (WHO, 2007) 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 working 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.

**Future Directions**

On the basis of this concept paper, we suggest:

1. That a coordinated, people-centred public health approach is implemented across the state for Victorians living with intellectual disability who are approaching the end of their lives, and that this approach is evaluated.

2. That the palliative care and disability sectors collaborate at state, regional and local levels to ensure people with intellectual disability can receive end of life care in their preferred place. At state level this requires the collaborative review and development of healthy end of life policies, at regional level partnership between services, including the acute sector, and at a local level, services, individuals and community organisations collaborating to support people to die in their home.

3. That end of life resources are developed in partnership with the disability sector, and that these resources take into consideration the structural, cultural and practical issues in disability and palliative care services so that residents are afforded the opportunity to die at home if that is their wish. Creative and concrete approaches to healthy dying and bereavement and legacy initiatives are implemented and evaluated.

4. That legislation, policy and protocols are reviewed to reduce structural barriers to residents being afforded the choice to, and receive care in their home, if that is their wish. Organisations are reoriented to provide end of life care in residential services.

5. That a funding model is created that allows residential services to access resources to support a resident to die at home. Access to modest funds through an expedited application/approval process will provide choice for a resident to stay in their home. Staffing a ‘house’ from 9-3pm with a disability support worker, and funding an ‘active night’ model, will be more cost effective than hospitalisation for end of life care, and will provide better outcomes. A dedicated portfolio within DHHS DAS will expedite the implementation of end of life policy, planning and practice in residential services across the divisions.

6. That the palliative care sector map the incidence of people with intellectual disability living in their catchment area and reorient services specifically to ensure that they are catered for both in access and service provision.

7. That the acute sector routinely assign in-house Social Workers to people with ID to facilitate appropriate discharge planning for end of life care in the residential services.
(non-medical model) to engage appropriate services for care provision, and that family and disability support workers are included in this process.

8. That an ‘end of life section’ in mandated health checks for people with disability, such as the yearly Comprehensive Health Assessment Program (CHAP) visit with the resident’s GP is investigated as a way to embed systematic assessment and monitoring of deterioration, thereby triggering a Palliative Approach. Including the ‘surprise question’ in CHAP, and engaging disability support staff in assessing deterioration, could facilitate early detection of illness. Likewise, Advance Care Plans (ACP) can be reviewed at the scheduled visit.

9. That people with intellectual disability living in the community with family or elderly parents, or independently with community support services are considered and further investigation is scheduled.

For further information or to discuss the contents of this paper, please contact Andrea Grindrod (Health Promotion Officer) or Bruce Rumbold (Director) of the La Trobe University Palliative Care Unit.

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Appendix

A. Solution Based Matrix

B. Disability End of Life Implementation Strategy

C. The 13 European Norms and a Victorian Implementation Strategy: A Comparison

D. A Public Health Framework for Disability End of Life Care
<table>
<thead>
<tr>
<th>SOLUTION BASED MATRIX</th>
<th>LA TROBE UNIVERSITY PALLIATIVE CARE UNIT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PALLIATIVE CARE, HEALTH &amp; DISABILITY</strong></td>
<td><strong>Establish Government and Organisational Policies (Structural)</strong></td>
</tr>
<tr>
<td>Create structures that support good end of life care</td>
<td>Promote healthy and inclusive approaches to end of life</td>
</tr>
<tr>
<td><strong>Solutions for Structurally Based Issues</strong></td>
<td><em>Instigate state level collaboration</em></td>
</tr>
<tr>
<td><em>Review relevant inter-sectoral policies creating practice based problems (medication, NFR policy, hospital discharges)</em></td>
<td><em>Establish monitoring and reporting mechanisms in the palliative and disability sectors</em></td>
</tr>
<tr>
<td><em>Establish monitoring and reporting mechanisms in the palliative and disability sectors</em></td>
<td><em>Create access to funds to keep residents at home</em></td>
</tr>
<tr>
<td><em>Palliative care services map and report on vulnerable populations (including ID) in their catchment area and design service strategies to reach them and meet their needs.</em></td>
<td><em>Introduce flag systems to ensure discharge planning in the acute sector is reviewed (outcomes are always better when the hospital Social Worker is involved (LMRPCC, 2015)</em></td>
</tr>
<tr>
<td><em>Introduce flag systems to ensure discharge planning in the acute sector is reviewed (outcomes are always better when the hospital Social Worker is involved (LMRPCC, 2015)</em></td>
<td><em>Include and end of life section in the mandatory annual GP CHAP review for residents.</em></td>
</tr>
<tr>
<td><strong>Solutions for Culturally Based Issues</strong></td>
<td><em>Create and implement organisational policy and protocols on healthy end of life and bereavement that normalise death as part of residential services.</em></td>
</tr>
<tr>
<td><em>Fund and/or support creative legacy projects to provide concrete learning experiences for residents on death and dying, and to promote healthy bereavement through legacy and ritual initiatives in the house and at local churches.</em></td>
<td><em>Use organisational newsletters, community development and creative arts projects for residents and engage palliative and pastoral care volunteers, as well as local service groups, churches and family.</em></td>
</tr>
<tr>
<td><strong>Solutions for Practical Issues</strong></td>
<td><em>Develop organisational policy and protocols that:</em></td>
</tr>
<tr>
<td><em>Facilitate collaboration between relevant services</em></td>
<td><em>Facilitate collaboration and partnership primarily, but not exclusively, between palliative care and disability services.</em></td>
</tr>
<tr>
<td><em>Create clear procedures for staff in end of life practice</em></td>
<td><em>Foster collaboration and partnership primarily, but not exclusively, between palliative care and disability services.</em></td>
</tr>
<tr>
<td><em>Reflect end of life care practice on the ground accurately</em></td>
<td><em>Adopt an asset-based approach to end of life care, recognising that staff are the organisations’ main asset.</em></td>
</tr>
<tr>
<td><em>Ensure organisational practice protocols between disability and palliative care are compatible</em></td>
<td><em>Provide guidelines and protocols on clinical and medical care of issues known to cause death in people with ID, such as aspirational pneumonia.</em></td>
</tr>
</tbody>
</table>
GOAL: People living in disability residential services in Victoria with a life-limiting illness receive timely and high quality end of life care in their place of choice

UPSTREAM: Healthy end of life legislation, policy, structures and systems are established in government and organisations that deliver good end of life experiences for people living with intellectual disability, their family and carers (including NDIS, reportable death processes and OPA)

DOWNSTREAM: People living in disability residential services in Victoria with a life-limiting illness receive timely and high quality end of life care in their place of choice
C. The 13 European Norms and a Victorian Implementation Strategy: A Comparison

The European consensus norms identify important issues to be considered in the end of life care of people with intellectual disability. A public health approach would argue that without equity of access (Norm 1), collaboration (Norm 8), education and training (Norm 12) and developing and managing services (policy and resources) (Norm 13), the practical issues identified (Norms 2-11) are less likely to be achieved. That is, equity of access, collaboration, education and training and developing and managing services are strategies (shaded in grey) through which to accomplish the remaining consensus norms, not standards to be met in and of themselves. A public health approach would also draw on other strategies outlined in The Ottawa Charter for Health Promotion, such as community development projects (e.g., creative arts), advocacy (e.g. for grave markers), capacity building (e.g. building resilience) and consumer engagement (e.g. involving residents in funerals). The White Paper outlines the areas to be addressed, but not how, and in what priority or order, they might be addressed to achieve sustainable change and efficient use of resources.

A combination of the two frameworks provides a comprehensive and complimentary approach:

<table>
<thead>
<tr>
<th>European Association of Palliative Care (EAPC) Consensus Norms 2015</th>
<th>Victorian Implementation Strategy that compares and includes the EAPC 13 Consensus Norms into a Public Health Approach to End of Life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Equity of access</td>
<td>Public Health Approach to End of Life for People with Intellectual Disability (LTUPCU)</td>
</tr>
<tr>
<td>2. Communication</td>
<td>Recognise expertise in disability sector, build organisational capacity, empowerment in participation</td>
</tr>
<tr>
<td>3. Recognising the need for palliative care</td>
<td>Early recognition of deterioration by health (acute and primary care) and disability sectors is included in service systems</td>
</tr>
<tr>
<td>4. Assessment of total needs</td>
<td>Formal partnerships between services ensure needs are met</td>
</tr>
<tr>
<td>5. Symptom management</td>
<td>Medical and nursing care provided in the home (advocacy and resources)</td>
</tr>
<tr>
<td>6. End of life decision making</td>
<td>Supported decision making for people with ID, legislation review and advocacy for equity of choice</td>
</tr>
<tr>
<td>7. Involving those who matter: family, friends and carers</td>
<td>Community empowerment, engagement and participation</td>
</tr>
<tr>
<td>8. Collaboration</td>
<td>Partnerships and reporting activities are formalised</td>
</tr>
<tr>
<td>9. Support for family and carers</td>
<td>Build capacity in staff and involve family and informal carers as routine practice in residential services</td>
</tr>
<tr>
<td>10. Preparing for death</td>
<td>Collaborative planning and normalising death by building resilience</td>
</tr>
<tr>
<td>11. Bereavement support</td>
<td>Build resilience and promote healthy bereavement processes. Advocate for specialist bereavement support for people with ID if required</td>
</tr>
<tr>
<td>12. Education and training</td>
<td>Include community development activities, creative arts projects and volunteers of community services, palliative or pastoral care</td>
</tr>
<tr>
<td>13. Developing and managing services</td>
<td>Reorient involved services to include end of life as outlined in the LTUPCU Disability HPPC Framework</td>
</tr>
</tbody>
</table>
D. A Public Health Framework for Disability End of Life Care

A public health approach to end of life care for people with ID is concerned with the barriers preventing people with ID from experiencing a good death, understood as having choice about place and mode of care, as well as the experiences of all those involved. Thus it takes a broader view than a person-centred approach that locates issues at the individual level. While this helps orientate services toward personal need, it can fail to take adequate account of the way the person is part of a complex organisational system. In the case of people whose experience is compounded by intellectual and physical disability, structural issues can result in dependency on organisations, little influence over the individual and support workers, and therefore vulnerability. For this reason, it is important to draw the individual and organisational relationship into closer alignment in end of life practice.

This can be achieved by identifying the immediate issues for individuals at practice level that prevent them, or enable them, to die in their home, if that was their choice. Doing so produces grounded knowledge of the fundamental issues experienced by residents, staff and family at end of life. Consistent with a health promotion approach, examining the issues from an ‘upstream’ or systems perspective assists with exposing the underlying cause of the persistent and repetitive ‘downstream’ or individual challenges. Creating systematic and sustainable change requires attending to strategies ‘upstream’, whether within organisations and government, or between departments, sectors and services. However, in bringing the needs of vulnerable individuals in closer alignment with the organisational structures that support them, it’s imperative that upstream initiatives are informed by the downstream experiences of people, and that the effectiveness of this connection is evaluated.

A multi-faceted approach as provided by the five action areas of The Ottawa Charter for Health Promotion (1986) offers a useful framework to address the range of issues involved. Drawing upon the core values and strategies of health promotion, such as sustainable change, capacity building and community engagement, empowerment and development, it offers a framework that assists practitioners to enable, mediate and advocate for disadvantaged or marginalised populations on end of life issues. More specifically, Kellehear’s Health Promoting Palliative Care (HPPC) (1999) aims to promote death and grief as a normal part of life 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.