## Futures Alliance – membership

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## Futures Alliance –
*Seeking Better Futures for People with a Disability who are Ageing*

The **Futures Alliance** has, and continues to, identify specific issues and current policy, and hence practice gaps, pertaining to people with a disability who are ageing.

**For People with a disability who are ageing (in line with the UN Convention on the Rights of Persons with Disabilities):**

- Genuine consultation about what they want and how their aged care needs will be met.

- Self-directed individual funding options with the flexibility to meet complex and changing needs.

- Recognition as a 'Special Needs' group within the Aged Care funding and legislative framework.

- Eligibility and access based on assessments that are sensitive to ageing changes for people with a disability.

- Access to all Commonwealth Aged Care Programs, including packaged and flexible care options.

- Access to health, and allied geriatric expertise.

- Ongoing research to provide a solid evidence base for policy, planning and service provision.

- Flexibility and collaboration between all levels of government and their departments.

- Funded partnerships between disability and aged care providers to allow collaboration and cross sector development.

- Professional development of a workforce that addresses ageing and disability issues in practice.

- Consistency between disability and aged care standards to ensure human rights and accountability.

**For Governments:**

- Improvements to planning and service delivery which minimises the likelihood of people with a disability who are ageing falling into crisis.

- One Government agency charged with the responsibility to co-ordinate planning and service delivery.

- Reductions in unnecessary use of expensive health interventions, such as hospitalisation

- A more equitable system, where people's needs are met irrespective of how they arise.

**For Service providers:**

- Better exchange of knowledge across aged care and disability services.

- More effective use of resources through better targeted assessment.

- Capacity to support people to continue to live in the community as they age.

**For Communities and Families:**

- Reassurance that people with a disability who are ageing will have their needs met.

- More effective support for carers

The Futures Alliance is an active group of interested individuals and organisations who meet monthly seeking systemic change to meet the needs of people with disability as they age.

The above comprises a summary of the Futures Alliance Blueprint (a copy of which is attached). The Futures Alliance continues to call for the above.

**Access to and choice of appropriate palliative care that meets the needs of people with disability**

This is a critical issue for people with disability. Whilst there are a number of reforms designed to increase choice, flexibility and community based living options (for example the National Disability Insurance Scheme), at the present time for many people with disability there is limited choice aroundend of life care decisions and palliative care.

We know that people with disability are living longer (Australian Institute for Health and Welfare, 2000) and for the first time achieving normative life spans. We also knowthere are limitations within the disability care sector to provide palliative care to people and for them to critically exercise decision making about palliative care and end of life.

There are multiple systemic issues identified in other inquiries that also intersect with this issue.

Some of the key ingredients that support decision making, choice and capacity to achieve end of life care at home include:

- environmental capacity to manage high support care

- established connections with allied health services to appropriately support aged care and palliative care needs for people with disability, including an appropriate capacity to understand and diagnose 'disability' vs. age related change.

- common understanding and perception about the rights of people with a disability to gain appropriate care

The broader experience for people with either physical or intellectual disability is the limitation of choice around end of life care and palliative care due to the above and key issues around home building adaptability, and responsiveness within the aged, disability and health care sectors to be able to adequately respond to changing health care needs, and ultimately end of life and palliative care wishes.

A Futures Alliance member has been engaged in a study around end of life care for people with disability with a PhD student through the University of Sydney. Some of the issues identified in their study are discussed below.

The United Nations Convention on the Rights of Persons with Disabilities recognises the rights of people with intellectual disability to obtain knowledge, and experience autonomy about the way life is lived(United Nations, 2006). Little is currently known about how this is enacted in the context of death and dying for individuals requiring palliative care (Ryan, Guerin, Dodd & McEvoy, 2011b). Weise, Stancliffe, Dew, Howarth and Balandin (under review) ask:

- If in the broader community, growing openness about dying and death has resulted in increased knowledge and thereby at least some autonomy about the manner of dying, does this also happen for people with intellectual disability as they approach death?
- Does the community actively facilitate opportunities to develop knowledge, or does the perception that people couldn't understand or cope, get in the way of achieving that right?

Community services staff play a crucial role in providing services and care to people with intellectual disability as the they age and approach the end of life; they provide both education and support to people with intellectual disability, to ensure they understand about dying and death. Recent research suggests that while staff recognise the importance of this aspect of their role their own understanding or knowledge of dying and death is variable and many feel unprepared to provide this support (Read & Elliott, 2003; Wiese, Stancliffe, Balandin, Howarth & Dew, under review; Ryan, Guerin, Dodd & McEvoy, 2011a).

The answer to the questions posed above is perhaps that people with disability are often overlooked in the development of palliative care services. These individuals have unique needs that are not always adequately addressed by standard models of palliative care practice, often falling between aged care, disability and palliative care provision. Similarly, families and carers supporting young people with disability requiring palliative care need better co-ordination of services to address their unique and often complex needs.

### Age related needs and palliative care

Increasing numbers of people with disability are ageing, and as a consequence an increased number require access to the breadth of health services, amongst which are services providing palliative care. Not only are there a greater number of people requiring palliative care, but often the length of time for which they require integrated and complex care is also increasing.

Some disability service providers estimate that over the next 18 years at least one in three people accessing services will experience age related health needs and will require access to appropriate formal and informal community-based supports to live actively with dignity and choice as they approach the end of life (Janicki 2010). Those most affected by this are people with intellectual disability, physical disability, a dual diagnosis, and those living on their own or with their ageing carers without any formal supports.

For this group of people who are ageing, significant change in personal support needs or circumstances can often result in inappropriate or early admission to aged care services. Due to the incapacity of community services to respond and meet changing needs, support to maintain living within ones home in the community as a choice is extremely limited.Importantly, the capacity to make decisions and choices about end of life care and support, available and expected within the broader community, is denied.

Identified complex trauma responses have been reported amongst people with disability who were previously institutionalized in large residential centres and who now live in the community, these responses often result in fear of health professionals and hospitals. In essence, they express a clearly articulated fear and anxiety response to a perceived threat of re-institutionalisation.

**Six issues to address in the meeting the palliative care for people with disability:**

### 1. *Communication, decision making and planning*

Communication and planning regarding palliative care should occur as soon as practical to ensure the individual and family have the opportunity to consider their options and make well informed decisions. Planning is important to avoid care or responses that are crisis driven, with ongoing and frequent decision making and review for appropriate end of life care (Stein 2008). For people with intellectual disability who are ageing, progressive problems around communication further emphasise the need for early advanced care planning. Uncertainty regarding how long people have got to live and to actively manage their life underlies the importance of practical planning.

Ways of enabling sound decision making involves the development of person-centred care plans which can be initiated early in the care process and involve a clear communication framework incorporating the individual, family and relevant health professionals. These plans can incorporate sensitive decisions regarding feeding support, ways of being comfortable when approaching death, deciding who should be present and include choices regarding resuscitation and revival.

### 2. *Continuity of care*

Essential to maintaining decision making and communication is the requirement for continuity of care. This is particularly important for older people with disability as they often experience an earlier onset of ageing issues and conditions. Continuity of care is also critical for young people with palliative care needs, as improved treatments can prolong survival which, in some instances, may lead to continuing care requirements through to adult services, and changes in service requirements.

Some disability support providers have a commitment to continuity of care to the people we support, however policies, programs and funding are separated into those for people with disabilities (under 65) and for people who are ageing (over 65). This separation creates delineations by program and across jurisdictions that inhibit

the capacity to respond flexibly and appropriately to the needs of a person across their life. There are also significant resource restrictions that impact on the choices available and the individuals' ability to plan for the future.

Policies that facilitate continuity of service provision and reduce program silos are required to address the needs of people with disability, both young and old, requiring palliative care.

Service innovation, as demonstrated by some providers is required, to enhance their capacity to respond to the changing needs of people with disability ageing, to prevent premature admission into Aged Care facilities, to have cohesive service delivery options, to maintain quality of life, community based engagement, choice and control.

### 3. Gaps in service – inadequate diagnosis and treatment regimes

Recognising the need for palliative care can often be difficult, and defining the population who require palliative assistance is a continuing challenge. When there is a gradual progression of illness, there is often no easy way to identify when to commence palliative assistance. For those ageing individuals with intellectual disability and high nursing support needs this becomes more complex and harder to identify; consequently appropriate palliative care may be delayed or never initiated(Centre for Development Disability Studies, 2004).

Factors leading to the under-diagnosis and under-treatment of general health problems for people with intellectual disability are similar to those constraining quality palliative care assistance and can result in poor assessment and control of symptoms. Factors contributing to under-diagnosis and under-treatment include:

- difficulty communicating or recognising symptoms as a result of cognitive and communication impairments,

- reliance on family or carers to provide medical history,

- anxiety or challenging behaviours can make physical examination difficult,

- negative attitudes and perceptions about quality of life for people with intellectual disabilities,

- clinicians attributing symptoms to the disability rather than underlying health conditions.

- Tendency for people with disability to experience a higher level of morbidity than the general population, with health problems often being multiple, chronic and complex (Centre for Development Disability Studies 2004, Lennox& Kerr, 1997).

## 4. *Setting of palliative care*

Choice and control over where to receive end of life care needs to be afforded to people with disability. For older people the opportunity to age and die in- place allows them to remain close to established formal/ informal support networks either in their own home (which may/should include a group home/or other setting defined as home by each person). Young people with disability need to be supported to receive palliative care in a setting of their choice, including their home. It is important that people with disability, irrespective of age, have the opportunity to live and die as they choose and avoid the inappropriate placement into aged care facilities or to undergo hospitalisation.

Capacity to achieve this objective lies firstly in home building design, to Bronze star accessibility standard, and therefore capacity to support people with high support needs. In NSW, a design guide has been introduced for planned new accommodation for people with disability and provides for this design standard (ADHC).

Currently this objective is not achievable with existing 'disability' homes or community based homes that people live in.  This is a significant barrier to the capacity of the health system to provide palliative care.

The following case studies provide an illustration of the experiences of people with disability.

**Case study 1:**

*Susan was 56 years old, had been a faithful and loyal employee to an organisation for 40 years. Susan's father passed away many years ago and she lived with her mother until she passed away four years ago. Susan and her mother did not receive any formal support until 2007, when they were fortunate to able to get some in-home support that helped Susan's mother manage and plan for the future. When Susan's mother passed away, Susan had in-home and community-based support in place and had great informal support within her local community.*

*Susan was diagnosed with cancer three years ago. She wanted to be at home but was not able to, as her home was not able to support her end of life care support needs. She did not want to be in hospital, and kept asking to go home. Susan passed away in mid-2011. On a positive note, she died surrounded by her many loving neighbours, extended family and friends.*

*Case study 2:*

*George had lived in supported accommodation for over 20 years. He was retired from his day program but still participated in the life of the home and retained close family contact. Due to a range of complex health and ageing issues he was eligible for additional support to enable him to 'age in place'. Shortly after joining his 'seniors program' George was diagnosed with throat cancer; treatment options were discussed by the medical specialist with him, his family and his support team. After months of monitoring his condition it became apparent that treatment options were limited. George was supported in the difficult decision-making to plan for his end of life care and he made clear his wishes to remain in his own home to the end. A palliative care team (PCT) referral was introduced to assist the planning process and a PCT Plan was prepared in consultation with George and his extended family. The service promoted subsidy to ensure his wishes to remain at home were met, introduced joint staff training with the PCT and additional staff time to ensure his care and personal needs were met. George's spiritual needs were met by a visiting church pastor, this support assisted him greatly to come to terms with his end of life stage. PCT staff provided excellent support to the NGO staff team, particularly in respect to monitoring care, pain management, nutrition and staff coaching on palliative care needs. George died peacefully and pain free, aged 68 years, in his own home surrounded by his friends on a Saturday morning in 2011.*

Building design is a critical issue to support community based living options, and to provide choice for people with disability. The first strategy is to build homes that will provide an environment where higher levels of support and care are able to be provided. Universal building standards and designs should be adopted as public policy – or bronze star building guidelines.

Community based and government funded organisations should be supported in their existing efforts, and to encourage innovation. Housing is a critical issue on the Federal and state agendas, and accessibility needs to be included as a high priority. Housing accessibility and meeting the needs of people with disability/s (in a way that meets diversity of needs) is not evident in terms of public policy, with a view thatpeople with disability have access to a home that is affordable, of high quality and accessible, and to provide continuity of care/support and to prevent premature admission to Aged Care and to support people who choose to die in their own home.

The capacity to meet the high support needs of people with disabilities as they age is inhibited by lack of appropriate community housing options, access to nursing supports and staffing resources to increase the level of care as required.

We are also seeking partnerships to support our endeavors to build affordable and accessible housing. Partnerships between housing providers and disability services, or directly with people with disabilities, are critical to enable the integration of housing and support to provide choice and control for people who choose to die in-place.

5.  *Partnerships and cooperation between palliative care providers and disability sector*

To enable ageing people with disability and families of young people to plan for the end of life in their home, greater integration with allied health services are needed. Fragmented services networks can/continues to result in inconsistencies in the level and quality of care afforded to individuals and result in unwanted hospitalisation.

Partnerships between palliative care, ageing, disability and health services are required to facilitate collaboration and cross-sector development. Engagement between multidisciplinary care providers and a focus on the family/or other significant care provider will enable people with disability, their family and carers to reach goals identified as part of an individual's advanced care plan. Access to quality care at home may enable greater engagement with individuals' wishes, the capacity to meet these is not always possible in acute care medical settings.

A greater integration of services including: physiotherapy, specialist palliative care nurses, hire of needed equipment, counselling and emotional support as well as respite for carers, can lead to better organisation and co-ordination of support at home. The recent introduction of the Medicare Locals should help facilitate this process.

### 6. *Workforce development - ageing, disability and palliative care*

Staff development and training is needed across disability, ageing and end of life care; for example in the areas of ethics, understanding end of life care needs, planning advanced care, sensitive communication skills and ways of delivering care, as well as assessing the decision making capacity of individuals with intellectual disability (Stein 2008). Greater recognition for staff training across these sectors and disciplines will contribute to improved co-ordination and provision of care in a responsive needs based fashion.

### Conclusion / Recommendations

1. People with disability should be able to and have the fundamental human right to access quality palliative care and end of life support.

2. People with disability have the right to self-determination and to exercise full choices in the where and how palliative care should be delivered

3. When people with disability choose to remain at home to die then resources to provide ongoing and additional support should be available in a timely fashion.

4. All planning for end of life care should be person-centred and respect the wishes of the person with a disability – this means their full inclusion, participation and informed consent to any planning recommendations.

5. Disability Services supporting people with a disability need help and resources to ensure that staff competencies, capacity and allocations can deliver the right level and quality of end of life support.

6. Disability Services also need assistance to ensure safe and appropriate home environments, equipment and facilities to deliver end of life care

7. PCT teams should be adequately resourced to support people with disabilities and their support networks and be sufficient to facilitate quality palliative care in the persons own home.

8. Additional education and training is needed with tertiary and primary health care professionals in understanding the unique needs of people with disability and the promotion of rights to self-determination and full inclusion in decision making

## References

Australian Institute for Health and Welfare (2000) *Disability and ageing: Australian population patterns and implications*. Canberra: AIHW.

Centre for Development Disability Studies (2004) *Palliative Care in People with congenital or acquired intellectual disability and High nursing support needs. Report to the Department of Ageing, Disability and Home Care*. Sydney: NSW Department of Ageing, Disability and Home Care

Janicki, MP. (2010). Aging adults with intellectual disabilities: Perspectives on emerging service concerns. *Journal of Special Education and Rehabilitation*, 11 (1-2): 114-129.

Lennox, N.G. & Kerr, M.P. (1997) Review: Primary health care and people with an intellectual disability: the evidence base. *Journal of Intellectual Disability Research,* 41:5, 365-372.

Read, S., & Elliott, D. (2003). Death and learning disability: A vulnerability perspective. *The Journal of Adult Protection,* 5:1, 5-14.

Ryan, K., Guerin, S., Dodd, P., & McEvoy, J. (2011a). End-of-life care for people with intellectual disabilities: Paid carer perspectives. *Journal of Applied Research in Intellectual Disabilities,* 24:3, 199-207.

Ryan, K., Guerin, S., Dodd, P., & McEvoy, J. (2011b). Exploring the experiences of people with intellectual disabilities when service users die.*British Journal of LearningDisabilities*, 39:4, 259-265.

Stein, LM (2008) Providing palliative care to people with intellectual disabilities: services, staff knowledge, and challenges*. Journal of Palliative Medicine*, 11:9, 1241 – 1248.

United Nations. (2006). Convention on the Rights of Persons with Disabilities. Retrieved 18 August 2011, 2011, from
http://www2.ohchr.org/english/law/disabilities-convention.htm

Wiese, M., Stancliffe, R. J., Balandin, S., Howarth, G., & Dew, A. End-of-life care and dying: Issues raised by staff supporting older people with intellectual disability in community living services. *Journal of Applied Research in Intellectual Disabilities,* under review.

Wiese, M. Stancliffe, RJ. Dew, A. Howarth, G& Balandin, S. Experiences of community living staff engaging older peoppple with intellectual disability to know about dying as he end of life approaches. *Journal of Intellectual Disability Research*under review.