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## Meeting the End of Life Needs of Older Adults with Intellectual Disabilities

Philip McCallion<sup>1</sup>, Mary McCarron<sup>2</sup>,  
Elizabeth Fahey-McCarthy<sup>3</sup> and Kevin Connaire<sup>4</sup>

<sup>1</sup>University at Albany,

<sup>2,3</sup>Trinity College Dublin,

<sup>4</sup>St Francis Hospice, Raheny,

<sup>1</sup>USA

<sup>2,3,4</sup>Ireland

### 1. Introduction

Palliative care for adults with intellectual disabilities has come to the fore as an issue only in recent years. This was and to some extent continues to be a largely hidden population in general health care, services were largely provided within their own intellectual disabilities services system, aging was the exception rather than an expectation and there were beliefs that people with intellectual disabilities themselves were not able or ready to make decisions about their end of life care. Some of these assumptions were never true but increases in longevity, onset of chronic diseases such as Alzheimer's disease and the development of palliative delivery in multiple countries are changing this picture (Fahey-McCarthy et al., 2009; McCallion & McCarron, 2004; & Tuffrey-Wijne, et al., 2007).

### 2. The demography of aging and chronic illness in people with an intellectual disability

Estimates suggest that life expectancy for people with an intellectual disability have increased from an average 18 years in 1930 to 59 years in 1970 to 66 years in 1993 (Braddock, 1999), with projected continued growth to match life expectancy of the general population (Janicki, Dalton, Henderson, & Davidson, 1999). By 2020 the number of persons with intellectual disability aged over 65 is projected to double from 1990 estimates (Janicki & Dalton, 2000). Many of the same socioeconomic and environmental factors in longevity improvement for the general population (clean water, decline in infectious diseases, improved living and nutritional standards, and disease and risk factor management - see Friedman, 2010) have been a feature for people with intellectual disability, but other contributors have been advances in and extension of medical care, advocacy and self-advocacy, and the development by providers of quality living environments and their support of enriching lives (McCallion & McCarron, 2007). Living in the community and improved economic status are likely to be the socioeconomic and environmental factors to drive continued increases in longevity for people with intellectual disability, but attention to disease and risk factor management are increasingly a feature for this population too, as an augmented life expectancy also

exposes a growing number of persons with intellectual disability to age-related diseases and challenges the health care they receive.

- Individuals with intellectual disability (ID) have a greater variety of health care needs compared to those of the same age and gender in the general population (US Department of Health and Human Services, 2002; Haveman, *et al.*, 2010)
- People with intellectual disability have 2.5 times the health problems of those without ID (Van Schrojenstein Lantaman-De Valk *et al.*, 2000)
- Rates of psychopathology are considerably higher in individuals with an intellectual disability compared to the general population (Fletcher *et al.*, 2007)
- People with intellectual disability are more likely to lead unhealthy lifestyles which contribute to the development of physical ailments in later life (Evenhuis *et al.*, 2001; WHO, 2001).
- Health problems of persons with intellectual disability are not being recognised (Merrick, *et al.*, 2002; Cooper *et al.*, 2004).
- The experience of poor health and early mortality among people with ID may be related to the location and types of health care services people with ID have received over a life time as well as in their older years (see for example Strauss *et al.*, 1998).
- There is a lack of specialist knowledge and training amongst multidisciplinary and health team members (McCarron & Lawlor, 2003).
- People with intellectual disability do not access health promotion and health screening services to the same extent as peers without disability (Iacono & Sutherland, 2006).

### 3. The challenge of Alzheimer's disease

Another feature of older age is exposure to risk of Alzheimer's disease and other dementias. This is particularly true for older people with Down syndrome who are uniquely at risk of developing Alzheimer's dementia at earlier ages. Current estimates are that 15-40% of persons with DS over the age of 35 years, present with symptoms of dementia and consequently, their related declines are precipitous (Prasher, 1995; Prasher *et al.*, 1998). Onset is also earlier with the mean age of dementia in persons with Down syndrome being estimated at 51.3 years.

Despite the pressing concerns, responses to Alzheimer's disease issues for people with intellectual disability have tended to be reactive rather than proactive. Providers are faced with unanswered questions regarding how their resources and skills may best be pooled, as well as what service models/developments need to be undertaken, and by whom (Bigby, 2002). A question remains as to what care setting is most useful in addressing and responding to dementia care needs in terms of both cost effectiveness and quality of life outcomes. Differences in philosophies, terminologies, fiscal arrangements and priorities complicate these issues (McCallion & Kolomer, 2003; Wilkinson & Janicki, 2002). The impact on family carers is at an even earlier stage of response (McCallion, Nickle & McCarron, 2005).

In fairness to providers, staff and families, these are new care situations and there is a need for evidence-based models for care if resolution is to be realized, institutionalization and re-institutionalization avoided, quality of life maintained and costs contained. Research is still responding to this challenge.

Very different issues present when individuals have symptoms of dementia and they challenge traditional staffing approaches and philosophies. Staffing numbers and patterns, and the training of staff has more usually been focused upon client groups who are young and middle adult, and on supporting and promoting the independence of persons with intellectual disability who are in jobs and interested and ready for community participation. The inevitable decline associated with dementia challenges this programming philosophy and there has been a danger within intellectual disability services that when dementia presents, providers will seek transfer to other, often more expensive and restrictive alternatives. Instead, there are opportunities in supporting aging in place and in understanding the role of specialized units for people with intellectual disability and dementia (Janicki, et al.2002). Finally, the traditional intellectual disability services funding assumption of fixed needs is challenged by new needs, e.g., 24-hour staffing where overnight staff were not previously needed, more frequent hospitalizations and emergency room use as symptoms of both dementia and co-morbidities increase and environmental management challenges such as falls, wandering and safety concerns occur. Responses to these new challenges are too rarely planned and are often unprepared for the end stage of disease even when maintaining a person in place is intended (Janicki, et al., 2002; McCallion et al., 2005). Data gathered to date suggests that service redesign for dementia is needed at individual, staff, residential/programming unit and organizational levels (McCallion & McCarron, 2004). Equally, approaches and assumptions may need to be re-examined at end stage disease (McCarron et al., 2010). It is also important to recognize that the living situations and social networks of people with intellectual disability may be different from those of other patients with whom palliative care comes in contact.

### **3.1 Living situations**

The majority of people with an intellectual disability live with family or independently but a considerable number have lived most of their adult lives in staffed out of home situations, and rather than being employed have attended workshops and day programs specifically for people with intellectual disability (Haveman et al., 2011). There is a strong likelihood that as adults with intellectual disability get older that they will have small social networks and that paid staff will have significant roles in those networks often occupying personal and friendship roles equivalent to those usually seen in family members (McCarron et al., 2011). It is important that palliative care staff recognize and include in their planning and service delivery this unique aspect of lives of people with intellectual disability.

### **3.2 Responding to end of life issues**

The core philosophy that has shaped current intellectual disability services has emphasized a citizenship model of care, i.e., that a person with an intellectual disability be recognized by other people as an individual who is a full member of society (Duffy 2003). As a citizen, the person with intellectual disability should have choice about where to be cared for and where to die and staff are challenged by how then to respond to the additional care needs of the person who is on a journey with a terminal illness (Blackman & Todd, 2005). Many intellectual disability services are poorly prepared to meet and respond to end-stage dementia in terms of the suitability of the service environments and the skill mix and knowledge base of staff (McCallion & McCarron, 2004).

The need to consider palliative care for persons with an intellectual disability is now receiving attention (Blackman & Todd, 2005; Ryan & Mc Quillan, 2005) as it is for the care of persons with dementia (Kitwood, 1997). However, a University of Sydney review (DADHC, 2004) reports difficulty still exists in the initiation of palliative care for persons with intellectual disability particularly since staff in intellectual disability services do not normally hold palliative care skills. Ng and Li (2003) go further, specifically citing a lack of knowledge of effective communication with the dying person and a lack of knowledge about bereavement support for carers of persons with intellectual disability.

Similarly, palliative care services have traditionally been provided predominantly to persons with malignant disease. There are challenges such as the lack of recognition and acceptance that dementia is a terminal illness and the difficulty in defining of the terminal stage of dementia (Lynn & Adamson, 2003; Lloyd-Williams & Payne, 2002). This is often further confounded in persons with intellectual disability by the level of pre-existing intellectual impairment and sometimes pre-existing high dependency levels (McCarron et al., 2010). Palliative care specialists often lack the knowledge and skills necessary to communicate effectively with persons with intellectual disability and may have limited experience in working with persons with dementia (Ryan and McQuillan, 2005). Although generally accepted that palliative care principles should be extended to other groups with terminal illnesses such as dementia, much work remains from a policy, resource and educational perspective to operationalize this intent (Luddington et al., 2001; Lloyd-Williams & Payne, 2002).

### **3.3 Merging palliative care, dementia and intellectual disability care principles**

Lynn and Adamson (2003) suggest that models of hospice care do not apply well to persons with chronic illness such as dementia because palliative care is seen as turning away from conventional (active/acute) care when persons with dementia instead require a mix of both kinds of care, particularly in the early stages of the disease. Others (Sachs et al., 2004) cite barriers such as the unpredictable nature of dementia and issues with assessment and symptom management. In addition, professionals and family have difficulty in viewing dementia as a terminal condition. Yet the person centered approaches in dementia care concerned with maintaining a quality of life for the person, supporting the persons in living until they die and ensuring that family/carers or persons close to him/her are included in their care (Downs et al., 2006) marry well with the palliative philosophy.

Indeed, opportunities lie within person-centered care to address both dementia and intellectual disability concerns. But in the application of palliative care, there is also a need to consider knowledge and skill issues in 1) relationship-centered care, 2) caring for a person with an intellectual disability, 3) caring for a person with dementia, 4) facilitating grief and loss, and 5) disenfranchised grief.

### **3.4 Person-centered care**

The person-centered challenge for palliative care lies in finding agreement amongst the individual, the physician(s), the primary caregiver, and the hospice team on expected outcomes in relief from distressing symptoms, the easing of pain and/or the enhancement of quality of life. Such ideas are not new to intellectual disability services or to dementia care. In intellectual disability services, there are well established systematic processes for

the discovery of an individual's gifts, capacities, experiences, core beliefs and dreams. The collaborative development of plans by service providers to realize those dreams is enhanced by the commitment to the individual by valued persons who help to realize the plan (Abery & McBride, 1998). In dementia care, Kitwood (1997) argued that as well as meeting physical needs, the enabling of the exercise of choice for the person, the use of the person's abilities, the fostering of the expression of his/his feelings and enabling him/her to live in the context of relationship, were also critical to his/her care. Being included means being part of a group and if this need is not met the person can go into decline or retreat.

### **3.5 Relationship-centered care**

Critiques of person-centered care are beginning to emerge (Adams & Grieder, 2005). Nolan, et al., (2001) acknowledge that person-centered care has had a far reaching impact on care in dementia but it is not enough to consider the individual without considering his/her relationships. Relationship-centered care is proposed for situations where relationships have developed over long periods of time such as in care homes (Nolan et al. 2006) and intellectual disability care settings. Dementia care triad, models of relationship-centered care recognize that there are at least three people, the person being cared for, the carer and one or more health and social care professionals (Adams & Grieder 2005), and may further include other people involved in the care of the person. The approach to care sees health care as a human activity given meaning by people within relationships (Tresoloni & Pew-Fetzer 1994). This view also resonates for people with intellectual disability (McCarron et al., 2010)

#### **3.5.1 Knowledge and skills of caring for a person with an intellectual disability**

A lack of knowledge of the needs of persons with intellectual disability by staff in general acute medical settings has been identified as leading to diagnostic overshadowing and unexpected and unexplained deaths (MENCAP 2007). Tuffrey-Wijne (1998) and Lindop and Read (2000) have identified (1) a need to be able to interpret non-verbal and alternative communication strategies and (2) the assessment and management of pain as two major educational needs for nurses in general practice to care efficiently for this population. For staff in intellectual disability settings there is an additional need for training and education about the ageing of persons with intellectual disability and the implications of care for a person presenting with symptoms of dementia (McCarron & Lawlor 2003). As persons with intellectual disability experience terminal illness and approach their end of life, this poses further challenges for the staff in intellectual disability settings. Hospice and other palliative care staff must also be equipped to understand the care of persons with intellectual disability (McCallion & McCarron, 2004).

#### **3.5.2 Knowledge and skills of caring for a person with dementia**

Regarding care for the general population with dementia, McCallion, (1999) reported that care assistants in nursing homes identified a need for education on communicating with the person with dementia and on managing behavioral issues. Despite such requests, there has been minimal training for staff or carers. Kitwood (1997) argues that this may result from

society's fear of ageing, illness, mental illness and death as well as the lack of understanding of dementia. He argues that good quality and sensitive interactions between carers and individuals with dementia are essential for good care (Kitwood 1997). Similar needs have been identified for staff in intellectual disability settings including their need to know how to recognize and manage dementia-associated changes in the person (McCarron & Lawlor, 2003). Sachs et al., (2004) go further, observing that staff should understand the need for early planning of care for the person with dementia, and ensuring continuity of care throughout the trajectory of the illness at early, mid and late stages. The diagnosis of dementia in persons with intellectual disability is complex and the up-skilling of staff in intellectual disability services in the assessment and support of the person with dementia has become crucial, as has on-going education of staff and family on the needs and care issues for the person (McCarron & Lawlor, 2003). Nutrition and hydration also cause concern for family and staff because often "the act of providing sustenance symbolizes love and caring" (Solomon & Jennings, 1998:138). A new culture of care emerges that does not pathologize dementia. Instead it focuses on the uniqueness of each person and respects what s/he has accomplished and allows what s/he has endured to be understood compassionately.

### **3.5.3 Knowledge and skills of culturally competent caring**

There is a need to deliver culturally competent care (Tuffrey-Wijne, 1998). Culture affects every aspect of a person's being (Tracey & Ling, 2005). Broad culture-specific issues have previously been identified in relation to terminal illness disclosure, breaking bad news, advance planning and locus of decision-making (Searight & Gafford, 2005). Some cultures advocate explicit disclosure of diagnosis and frank planning for end-of-life care (Candib, 2002). Other cultural groups place higher value on family connectedness than on individual autonomy and may value life at all costs over an easy death. In intellectual disability services there are long established trends of differences in culture between the person, the staff carer and the organization providing care (McCallion & Grant-Griffin, 2000). In intellectual disability settings, more concretely, in many aspects of care McConkey (2004) identified that new staff members tend to rely heavily on verbal communication; yet asking too many questions of the person and the family may actually make situations more complex and impede decision-making. Looking specifically at issues in aging and health, McCallion et al., (1997) identified that professional staff in intellectual disability services may also not be sufficiently sensitive to cultural differences and influences among family and among care staff and may fail to recognize the strengths in other cultures. Culturally appropriate care respects and recognizes the contributions of everyone involved including care staff.

### **3.5.4 Knowledge and skills of palliative care**

Staff in intellectual disability services are not generally prepared in palliative care skills (DADHC 2004). This is compounded by a clear lack of literature about the palliative care needs of persons with intellectual disability (Tuffrey-Wijne, 1997). Tuffrey-Wijne (1997) reported that while staff supported offering death and dying care in principle, they did not feel they had the expertise in practice. Furthermore, staff may be unprepared for the family dynamics around caring for someone with a terminal illness and the emotions involved. In

later work, Tuffrey-Wijne (2002) suggests that a more collaborative working relationship between intellectual disability staff and palliative care staff may improve care. Collaboration with specialist palliative care would also encourage greater exchange of expertise. Todd (2004) agrees that carers in intellectual disability services would benefit from education on what to report to the palliative care team and from information on what to expect in the progression of the disease/illness and how to interpret important changes which could indicate pain.

Findings elsewhere suggest that nursing staff who acquired knowledge about the use of drugs commonly used in the symptomatic and palliative management of patients, developed new confidence and found ways to make their assessments of the end-of life care needs of the patients more explicit to other practitioners, thus improving care (Watson et al., 2006). Whittaker et al., (2007) argue that frontline staff and their skills determine the quality of care delivered to people and there is a need for more training in psycho-social care, spiritual care and meeting cultural needs. Solomon and Jennings (1998) also report that medical and nursing staff would benefit from training in the pharmacological and non-pharmacological management of pain and other symptoms to improve palliation. These findings for care of the general population have been confirmed as needs too for care staff, nursing staff and medical staff within intellectual disability services (Fahey-McCarthy et al., 2010).

### **3.5.5 Knowledge and skills of addressing nutrition, hydration and pain concerns**

Feeding difficulties and challenges experienced as part of end-stage dementia care by persons with intellectual disability mirror those difficulties described in the generic care literature in persons with Alzheimer's dementia (Norberg et al., 1994; Biernacki & Barratt 2001; McCarron & McCallion, 2007). Lack of ability to self-feed, the difficulty of holding food in one's own mouth, chewing and swallowing concerns, agitation and distress, spitting, and food inhalation/aspiration all culminate in stress for the person, the family and staff (McCarron et al., 2003). For example, staff report that watching someone they know and care for who is now unable to eat/drink is difficult and they describe feelings of guilt and remorse when faced with this concern (Service, 2002). Staff carers and family are often attracted to what they perceive as the benefits of artificial nutrition and hydration (ANH), including the use of feeding tubes. End stage dementia and related end of life decision making is an emotional and value laden time. Given influences of cultural and religious values of the person, the family and at times care staff, emotions and relationship bonds and conflicts, limited ability to know and understand the wishes of the person, and a lack of undisputed outcome data to support or discourage use of feeding tubes (or alternative approaches) and other life sustaining treatments, making decisions regarding sustaining treatments such as feeding tubes for persons with intellectual disability and dementia present formidable clinical and care challenges. Work is needed on understanding the utility of tube feeding for persons with intellectual disability, where it fits within the continuum of palliative care, and how best to present and discuss these issues with persons with intellectual disability and dementia, their family members and staff carers.

Within the generic care literature there is little evidence to support the use of tube feeding in persons with advanced dementia (Mitchell et al., 1998; Finucane et al., 1999, Volicer, 2005). Perceived benefits of tube feeding in persons with advanced dementia such as preventing malnutrition and reducing risk of pressure sores, preventing pneumonia, promoting comfort

and improving functional status have not been upheld in the reported research (see Finucane & Bynum, 1996; Finucane et al., 1999; Volicer, 2005). However, there is a history of successful use of tube feeding among children and adults with intellectual disability that confounds the discussion of its implementation in end stage disease meaning that it is important that there be education around its implication at end of life (McCarron & McCallion, 2007).

Similarly, the assessment of pain in persons with cognitive impairment or intellectual disability has also always been identified as problematic (Regnard et al., 2003; 2006). Assessing pain in patients with Alzheimer's dementia appears to be even more complex again (Regnard et al., 2006). Specialist palliative care services must also recognize that the assessment instruments used for the general population for both pain and nutrition needs are rarely helpful for people with intellectual disability (McCallion & McCarron, 2004; McCarron & McCallion, 2007). Staff in intellectual disability services therefore would benefit from additional guidance from generic palliative care services on such issues as pain management.

### **3.5.6 Knowledge and skills of facilitating grief and loss**

Loss is broadly divided into the two categories of physical loss and psycho-social loss. When someone experiences the death of any loved one, there will be the potential for the loss to manifest in grief (Rando, 1993), the process of experiencing the psychological, behavioral, and social reactions to the experience of the loss. Mourning is then the cultural and/or public display of grief, often described in terms of uncomplicated grief versus complicated or unresolved grief.

Grief issues are often reported to be different in dementia compared to other terminal conditions (Sachs et al., 2004). Despite the findings of Moss and Moss (2002:202) that staff in hospitals and nursing homes are "not kin" and have "no lifelong ties with the resident" others argue that staff form relationships with the person with dementia and have their own grief issues (Whittaker et al., 2007). A services framework that emphasizes physical and medical care and sees psycho-social needs in relation to death as secondary (Moss & Moss 2002) fosters staff ideologies such as 'professional distance' that are linked to "disenfranchised" grief. In intellectual disability services many staff have lifelong ties with the person with dementia.

Staff caring for persons with an intellectual disability have also been found to be heavily involved in the rituals around the death of a person in their care (Dodd et al., 2005). Yet palliative care staff and some intellectual disability services administrators may still respond to staff in intellectual disability services as if the Moss and Moss 'distance' model applies, making this group particularly prone to disenfranchised grief.

Disenfranchised grief as a concept was first put forward by Doka (1989:4) as "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported". This concept validates grief which had not previously been acknowledged (Corr, 2002). Health care professionals "rarely grieve the death of patients", and "usually do not participate in funerals or mourning rituals for deceased patients" according to Lamers (2002:183). "Disenfranchised grief occurs when staff members perceive that their loss is not legitimized and that their relationship with the deceased does not entitle them to feel or express grief" (Moss & Moss, 2002:205).

Care-giving staff may also experience vicarious grief (Kastenbaum, 1989) where they identify with a surviving resident who was a long-term friend or room-mate. In intellectual

disability services such grief challenges staff in their supporting of surviving peers. Many staff in intellectual disability services want the people they care for to die in their own home and actively attempt to keep other services at a distance in the belief that they are more knowledgeable and sympathetic to this group (Todd, 2004).

Staff are often unprepared educationally to care for the dying and they struggle to give end-of-life care to the best of their abilities, providing lots of love and personal care (Todd, 2004). Institutional policies and procedures compound disenfranchised grief of staff when they do not support an overt grieving process (Lamers, 2002).

There is also disenfranchised grief for the other persons with intellectual disability in the home and for the family. There is both a long-standing belief that persons with intellectual disability do not experience the range of emotions of others including feelings of grief at the loss of family members and close friends/neighbors and, conversely, that they will not be able to “manage” the associated feelings (Yanok & Beifus, 1993). These beliefs and concerns are often used by family members to justify not informing persons with an intellectual disability of the death of parents and for not involving them in funerals and other death and mourning rituals.

It is not just a “family” problem. Todd (2002) points out that staff too have difficulties with the issue of death; family desires to “protect” the person become a convenient explanation for a lack of advocacy for death experiences and education for persons with intellectual disability. Yet persons with intellectual disability, as they age, are likely to experience losses through death often with major implications such as with the death of a parent that may mean they will have to move to a sibling’s home or to an out-of-home placement (McHale & Carey, 2002). Not having experienced death and mourning also means that many persons with intellectual disability will poorly understand death and not be prepared for their own deaths (Clegg & Lansdall-Welfare, 2003).

While death and bereavement in this population remains a poorly researched area (Todd, 2004), there is evidence that persons with intellectual disability do indeed understand the finality of death and have often formed bonds with family members and others and feel personal loss and grief. However, being shielded from funerals, even the announcement of death may mean that people with intellectual disability do not know how to or have the opportunity to express their grief (Yanok & Beifus, 1993).

Grief does surface. Symptoms of normal grief as defined by ICD-10 occur within one month of the bereavement and do not exceed 6 months duration. For persons with intellectual disability, later onset and longer duration of grief symptoms are more likely. Also, as well as with increased levels of depression, anxiety and distress, grief reactions in persons with intellectual disability are often manifested in behavioral difficulties. These behaviors are more likely to be viewed by family members and professionals as psychosocial concerns rather than as the expression of grief (Hollins & Esterhuyzen, 1997; McHale & Carey, 2002). Reflecting these findings, Dodd et al., (2005) identified a need for staff training to support the grieving process for people with intellectual disability.

#### **4. Best practices**

A recent study of collaboration and training needs among intellectual disability services and a specialist palliative care provider (Fahey-McCarthy et al, 2010) highlighted a number of critical steps in successful delivery of palliative care for people with intellectual disability:

- Raising awareness among staff in both systems of the philosophies underpinning care and the expertise inherent in both intellectual disability and specialist palliative care services.
- Recognizing staff in intellectual disability services as highly dedicated and committed to providing optimal care but sometimes lacking knowledge and specific skills, particularly in managing symptoms such as pain, constipation, dyspnoea and fevers and the skills needed in the siting sub-cutaneous lines, managing nutrition and hydration, and assessing pain/distress.
- Recognizing that staff in specialist palliative care offer skills around symptom management and an external source of support that may be vital to navigating final days.
- Equipping specialist palliative care staff to address their communication difficulties with persons with ID, and need for understanding of dementia, care needs of people with ID, current services structures in ID and where specialist palliative care fits and best addresses the gaps in current service provision.
- Given that many staff working in community group homes in intellectual disability services do not have nursing expertise/training, recognizing a need to re-evaluate the skill mix among staff in some of these care settings as more persons present with advanced dementia.

Tuffrey-Wijne (2002) and Todd (2004) have highlighted that when staff working in intellectual disability care are equipped to report important changes to palliative care staff, this has proven critical to good symptom management in terminal care.

A lack of understanding, experience, and skills in the management of pain and distress is reported to frequently result in the person with an intellectual disability being transferred from their usual home/care setting to a generic care setting/hospital and “bad deaths” are also described when staff have been unable to keep the person comfortable or at home to die (Fahey-McCarthy et al., 2009). Such reports support practices of collaboration, cross training, multi-disciplinary teams empowered to promote collaboration and the development of an understanding of when and how to involve specialist palliative care input into end of life care. Such involvement of specialist palliative care appears particularly needed for symptom management, i.e., the control of pain and dyspnoea and in the management of nutrition and hydration (Fahey-McCarthy et al., 2009). Due respect by palliative care for the competency and services offered by the intellectual disability services system should not preclude the development of supportive and consultative relationships between the two service systems and indeed comfort, caring and support of persons with intellectual disability in the advanced stages of dementia requires it.

Additional education and palliative care intervention guidelines are also needed. As Tuffrey-Wijne et al (2007) point out, available curricula are not usually targeted at staff responsible for day to day care. This gap in training needs to be addressed and policy and service provision should also ensure that there is specialist palliative support available to assist staff to operationalize guidelines and approaches (Fahey-McCarthy et al., 2009). Operationalization should include coordinating care with multidisciplinary care teams, increasing collaboration, communication and building of bridges with acute care settings and community based physicians working in intellectual disabilities, dementia and palliative care settings, and working with intellectual disability services staff to develop the ability to care for dying persons on site (Fahey-McCarthy et al., 2009; Solomon & Jennings 1998).

Approaches that draw upon the perspectives of staff within intellectual disability services and specialist palliative care encourage and support greater understanding of the core philosophies, common strengths and contributions to care offered by each service system. Such approaches offer insights that will potentially encourage greater creativity in determining the roles and timing of palliative care for persons with intellectual disabilities and advanced dementia (McCarron et al., 2010).

#### 4.1 Sources for best practice materials

Among the resources available, five deserve particular attention:

1. *Supporting Persons with Intellectual Disability and Advanced Dementia: Fusing the Horizons of Intellectual Disability, Dementia and Palliative Care: A training Curriculum.* The curriculum emerged from an effort to understand staff experiences in supporting persons with intellectual disability and advanced dementia. A cross section of intellectual disability service providers and a specialist palliative care provider in the Republic of Ireland were involved in the study. Their experiences were interpreted to gain an understanding of their education and training needs and this information was then the basis for an educational intervention which was designed, delivered and evaluated as a pilot effort with these services. A partnership approach which involved the Trinity College School of Nursing and Midwifery research team, intellectual disability service providers and a specialist palliative care service was crucial to success.
2. *End of Life Care: A guide for supporting older person with intellectual disabilities and their families* (Botsford & Force, 2004; McCallion, 2006).  
[http://www.nysarc.org/files/3213/0995/7606/Advocacy\\_Monograph\\_No.\\_3\\_2.22.11.pdf](http://www.nysarc.org/files/3213/0995/7606/Advocacy_Monograph_No._3_2.22.11.pdf)  
 A collaborative report involving both intellectual disability and hospice/palliative professionals providing guidance for staff and families on the policy context and day to day management strategies when persons with intellectual disability approach the end of life. The guide is supported with a cd-rom supplement also available through NYSARC, Inc.
3. <http://ddhospiceandpalliativecare.org/>  
 An online forum was developed in response to a series of training workshops organized across New York State to bring together Developmental Disabilities, Hospice and Palliative Care providers and advocates who have an interest in improving end-of-life and supportive care for persons with developmental disabilities, as well as their families and their staff caregivers  
 Goal: to improve end-of-life care for persons with developmental disabilities through greater utilization of hospice and palliative care services.  
 The forum was developed to provide a safe and accessible platform that would encourage a learning dialog and features a professionally facilitated discussion board where registered members are able to post questions and concerns and then receive answers from experts and/or their peers. Forum members also receive monthly E-Newsletters that provide up to date news, policy information, advocacy opportunities, education resources, practical materials and a current events calendar centering on Hospice, Palliative care and Developmental Disabilities.
4. *Let's Talk about Death.* A booklet about death and funerals for people who have an intellectual disability available from Down syndrome Scotland. This booklet may be

used both to prepare individuals with an intellectual disability to participate in decisions about their end of life care and to support peers of individuals who are dying. <http://www.dsscotland.org.uk/resources/shop/talkaboutdeath>

5. *The Palliative Care and End of Life Training Project* (Hahn et al., 2011). A handbook, specialized curriculum and short, intensive “Train-the-Trainer” training program for staff to address the unique palliative and end of life care needs of individuals with developmental disabilities who live in developmental centers. When training is developed in partnership with the staff who will use these training resources, it has the potential to sustain its use and to alter the care practices to address the palliative care needs of persons with intellectual disabilities. Joan.Hahn@unh.edu

## 5. Conclusion

Both United Nations and European documents on the rights of people with disabilities (Council of Europe, 2006; United Nations, 2006) emphasize that health and social care should be most influenced by the needs of the individual with a disability and call for equal enjoyment of rights and freedoms and respect for the inherent dignity of people with disabilities. Such a view is consistent with person-centered planning philosophies and World Health Organization (<http://www.who.int/cancer/palliative/definition/en/>) encouragement for “impeccable” assessment, prevention and relief of physical, psychosocial and spiritual suffering. There is much within the intellectual disability services system that will support such approaches for people with intellectual disability. However, Alzheimer’s disease and other dementias are fundamentally challenging this service system and there is a need for assistance, particularly with complex symptom management, assistance available through palliative care. Palliative care services are also being challenged; they have not traditionally served people with an intellectual disability, are not skilled in some of the unique communication and assessment challenges and also may not have extensive experience in dementia care. As noted in the best practice resource section, there are models for collaborative and supportive practice among intellectual disability and palliative care service providers but more work and related research is clearly needed if people with intellectual disability are to experience the same choice and comfort at end of life that is hoped for by everyone in society.

## 6. References

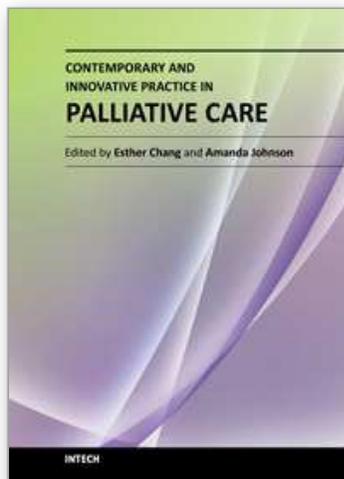
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Phone: +86-21-62489820  
Fax: +86-21-62489821

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