



**University of Dundee**

## **Overcoming barriers to grief**

Young, Hannah

*Published in:*  
International Journal of Developmental Disabilities

*DOI:*  
[10.1080/20473869.2016.1158511](https://doi.org/10.1080/20473869.2016.1158511)

*Publication date:*  
2017

*Document Version*  
Peer reviewed version

[Link to publication in Discovery Research Portal](#)

*Citation for published version (APA):*  
Young, H. (2017). Overcoming barriers to grief: supporting bereaved people with profound intellectual and multiple disabilities. *International Journal of Developmental Disabilities*, 63(3), 131-137.  
<https://doi.org/10.1080/20473869.2016.1158511>

### **General rights**

Copyright and moral rights for the publications made accessible in Discovery Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from Discovery Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain.
- You may freely distribute the URL identifying the publication in the public portal.

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

**Title Page**

Overcoming barriers to grief:  
supporting bereaved people  
with profound intellectual and multiple disabilities  
University of Dundee

Hannah Young\*

Hannah Young, Researcher, *PAMIS*, School of Education and Social Work,  
University of Dundee

\*Correspondence concerning this article should be addressed to:

*PAMIS*, Springfield House, University of Dundee, Dundee, DD1 4HN.

E-mail: [h.young@dundee.ac.uk](mailto:h.young@dundee.ac.uk)

This is an Accepted Manuscript of an article published by Taylor & Francis in International Journal of Developmental Disabilities on 28 Mar 2016, available online: <http://www.tandfonline.com/10.1080/20473869.2016.1158511>

## Abstract

Engaging people with profound intellectual and multiple disabilities (PIMD) in relation to issues of bereavement and loss may be seen as a complex therapeutic challenge. The author examines the barriers preventing them from engaging with therapeutic approaches and note that the extent to which the person engages with the grieving process partly depends upon how they are enabled to overcome these challenges. Through the lens of Worden's (2008) model, the author provides an assessment of the social, emotional and physical constraints that affect the person's experience of bereavement. Within this framework, suggestions and approaches for support are offered. This conceptual paper can be used to bridge the gap between theory and therapeutic practice, and provides the basis for future research involving this group.

*Keywords:* bereavement, profound intellectual and multiple disability, mental health, grief theories

Overcoming barriers to grief: supporting bereaved people with profound and multiple intellectual disabilities

Loss can be an incredibly painful, complex and confusing mix of experiences for someone with intellectual disabilities (ID) (Read, 2014). We may be increasingly more comfortable with having conversations around dying, death and bereavement more generally (Patterson et al, 2014), but are we getting any better at having those conversations with the most vulnerable people in society, including people with ID (Forrester-Jones, 2013; Wiese et al, 2013)? It is certainly the case that there is little recognition of the bereavement experiences of people with profound intellectual and multiple disabilities (PIMD) (Young et al, 2014a). Only several pieces of work, mainly in the UK and The Netherlands, have described some of those experiences and reactions to loss in this group. Moreover, in practice, bereavement counsellors may be perplexed by severe communication impairments, which present obvious therapeutic challenges (Clegg et al, 2003; Colman, 2003). Therefore, this paper is significant, to the researcher and practitioner, for how bereavement and healing is conceptualised in this group.

***Why do people with PIMD present as a distinct group?***

There are a variety of terms and definitions of PIMD within the international literature: ‘profound- ‘multiple/learning/intellectual disabilities’, ‘mental retardation’, ‘multiple handicaps’ (Nakken et al, 2002) and ‘mental subnormality’. Although terminology differs, there are some core elements to the ways in which ‘profound’ is defined. It is generally accepted that people with PIMD have the most severe cognitive impairments, with an IQ below 20 (Mansell, 2010). They are thought to be operating at a pre-verbal stage of development (Carnaby, 2004; Coupe O’Kane et al, 1998; Nind et al, 2001; Ware, 2003), which precludes the ability to act with intention, understand cause and effect, differentiate between subject and object and symbolically convey meaning. Overall, they are perceived as reflexive beings (Tang, Patterson & Kennedy, 2003), although this is extensively debated in ‘The PMLD Ambiguity’ (Simmons et al, 2014).

Against these proposed cognitive difficulties, many people with PIMD experience sensory impairments, (Kelleher et al, 1986; Evenhuis et al, 1998), epilepsy (Codling et al, 2008), respiratory problems (Wallis, 2008) and mobility limitations (Cleaver et al, 2009). Generally, they present as a distinct group in terms of the differences in their care needs and disabilities, which can be life-threatening (Pawlyn et al, 2008). More widely, these factors influence their ability to engage with their communities, live as active members of society, and express choice and control (Mansell, 2010).

What these definitions do not capture however, is the *profound* nature of people with PIMD as being a group which is difficult to know and understand with any great deal of certainty or insight. The Oxford Dictionary provides definitions of ‘profound’ as: “very great or intense”, “very deep” and “demanding deep study or thought” (Oxford Dictionary of English, 2015). Indeed, traditional approaches (e.g. cognitive psychology and behaviourism) have offered us very little light into their inner worlds and are restricted in their explanatory power of behaviour. Furthermore, these theoretical frameworks do not respect the profound mystery of this group. The argument here is that the nature of people with PIMD is not just specific to the individual’s cognitive limitations, but are also embedded within the wider experience of the world around them, and context-specific (Simmons et al, 2014).

### ***Conceptualising bereavement in relation to people with profound intellectual and multiple disabilities***

A theme that pervades the literature is the ongoing quest for the most suitable theory by which to understand bereavement and in those with ID. This search has always been complicated by the diversity of communicative abilities, which offer a wide variety of insights into their inner worlds. Research practitioners can be found acknowledging the ways in which responses to loss are expressed (Dodd et al, 2005) and seeking to identify a coherent framework within which to provide suggestions of support (Blackman, 2003; Read, 2014). In summary, applications of theory to the field have included task, phase and stage models of bereavement (see Read, 2014). Meeusen-van

de Kerkof et al (2006) is perhaps the first to explicitly apply theory to understanding bereavement in the profound group, and concentrates on cognitive development as a starting point from which to understand their experiences. This contribution will be explored further, but it seems potentially beneficial to strive for an encompassing conceptual model that might reveal a number of additional therapeutic approaches in this area. It is suggested that Worden's (2008) Four Tasks of Grief may be one such model to *facilitate* important considerations.

### ***Conceptualising bereavement in people with profound intellectual and multiple disabilities***

Worden's (2008) theory provides a complementary understanding of mourning; that the bereaved person, and those supporting them, can influence and change their experience of grief. He suggests that there are four tasks within the mourning process: to accept the reality of the loss, to process the pain of grief, to adjust to a world without the deceased and to find an enduring connection with the person. The use of Worden's (2008) theory, in the context of this conceptual paper, can be found in its ability to exemplify some of the tasks that we all engage with to some extent, but which may be complicated for people with ID and certainly for people in the profound group. Worden's (2008) theory assists us, perhaps paradoxically, to come closer to their bereavement experiences, as upon reflection of this theory we identify the many difficulties precluding engagement with the four tasks. Indeed, this challenges versus facilitation approach can be found in much of the literature relevant to this area (Luchterhand et al, 1998; Sormanti et al, 2011; Stoddart et al, 2002; Handley et al, 2013).

The aim of this paper is to utilise Worden's (2008) theory as a lens through which to examine bereavement experiences. It will suggest that a psychological, physical, social and spiritual analysis, in this respect, points to inclusive approaches which can overcome these barriers and respond sensitively. This is an important area of consideration, as this has not been previously studied in any great detail, in relation to this unique and often disenfranchised group.

#### **Task One: Accepting the reality of the loss**

*Cognitive impairment – justification for exclusion?*

For any of us to accept the reality of a loss, we must first come to know about that loss, but people with PIMD are often excluded from this. They make up part of the group for which death education is certainly considered inappropriate. It is argued that such people do not have the intellectual ability to understand complex concepts such as 'death' and 'dying' (Meeusen-van de Kerkof et al, 2006). Within this framework, people with PIMD are in the early phases of sensorimotor development (Piaget, 1954), a phase encompassing the concept of object and person permanence, but which is not, arguably, fully accomplished in this group. They claim that those things that are outside the realm of the senses do not exist to someone with PIMD. Lack of grief reactions are cited as support of this claim, although no strong empirical research is provided and a body of work is beginning to challenge this assumption (Phillip et al, 2005; Young et al, 2014a; Young et al, 2015).

This issue of cognitive impairment leads us to a further point that people with PIMD are perhaps the most disenfranchised group of the ID community, particularly in relation to mental health issues. This idea, developed by Doka (2002), highlights that grief can be disenfranchised when society does not recognise or accept that a person is experiencing loss and mourning. The few studies that have involved people with PIMD emphasise that we have not yet begun to include them as an integral part of the mental health literature and this has huge implications for practice (Sheehy & Nind, 2005).

#### *Supporting Acceptance of the Reality of the Loss*

Tuffrey-Wijne (2013) describes breaking bad news to people with ID as a process, which can begin long before the death of a loved one, loss or change. Similarly, in a framework of support, Read et al (2007b) emphasises the importance of education before participation, facilitation and intervention. Within this integrated framework, the authors suggest that these aspects be reflected in care delivery, from the level of the individual and family support through to organisational and national levels, with education serving the foundation for both the person and the carer. A case study is presented to illustrate the adverse effects of an approach that is counter to

this philosophy; Joan was not involved in her mother's funeral and subsequently experienced anger related to this exclusion. The authors highlight that had Joan's carers received adequate training they may have facilitated Joan's acceptance of the reality of the loss through inclusion in grieving rituals. This can be extended to include death education with people with ID themselves, and their families, which may also reduce risk of complicated grieving in the person.

Conversely, with the group of people with PIMD, Meeusen-van de Kerkof et al (2006) suggest that bereavement work should not focus on educating the person about death or dying, but instead provide concrete experiences of absence. Suggestions do not extend beyond supporting the person in response to changes in behaviour. However, the message of inclusion is strong: hospital visitations, attending funerals and visits to the grave can be incredibly significant places of meaning for the bereaved person and provide concrete experiences (Weeks, 2004). These events can provide experiences that help convey meaning. Of course, these are not the only opportunities that one has to experience loss, but they are arguably some of the most significant and memorable occasions, as they occur within a social setting with heightened emotions and reactions (Gaventa, 2014). A crucial point, because the innate capacities of intersubjective awareness (Trevarthen et al, 2001) do not preclude social referencing (the ability to read another and interpret their emotion) (Sorce et al, 1985).

### **Task Two: Process the pain of grief**

#### *Attachment experiences and affect regulation*

Natural emotions related to grieving can be painful and difficult to experience. Worden (2008) highlights that 'being with' and accepting the emotions of grief can move the individual to a place where the emotions are better regulated and not causing overwhelming distress. A plethora of evidence supports the significance of early interactions with the caregiver as being the foundation for affect regulation (i.e. the ability to manage stress) (Schore, 2001). A review of this area reveals that cognitive difficulties, and neurological damage, may affect a person's ability to utilise attachment behaviours and relationships as a function for affect regulation (Janssen et al, 2002).

People with PMLD may therefore be more vulnerable to the effects of loss, lack the internal resources to manage related emotions and ability to obtain external support. Against this backdrop, we also know that attachment style can be associated with the experience and intensity of emotional pain related to loss (Bowlby, 1980). This has consequences for complicated grief if the person had or experienced, as may be the case in people with PIMD (Schuengel et al, 2009; Naber et al, 2007), an insecure attachment to the deceased (Parkes, 2006; Dodd et al, 2014).

What has yet to be explored is the impact of the many losses that people with PIMD and their family carers will experience, in addition to attachment relationships. For example, what is the impact of the profound disability itself in relation to trauma (Sinason, 1986) and experience of loss (Gaventa, 2014)? In addition, throughout their lives they will experience loss in stressful transitions from school to adult day services (McBride et al, 2012), death of their peers (Hogg et al, 2006) and paid-staff turnover (Buntix, 2008). Furthermore, many people with PIMD live with their parents, often into their parent's elderly years due to their increased healthcare needs. The concern around this arises when the parent dies and the person must navigate through the transition of losing one's parents, leaving home and moving to a new place to live (Oswin, 1991). In view of these factors, the psychosomatic problems associated with loss in this group (Phillip et al, 2005), and the difficulties in differentiating these from the rudimentary poor health, further complicates this picture. When there are many changes in one's life, it may be cognitively and emotionally difficult for the person to deal with the initial loss and can contribute to psychiatric disorder. This is exemplified in a case study of a young man with PIMD (Dosen, 2005), in which a number of adverse life events (including loss) led to changes in socio-emotional and cognitive functioning that preceded a psychiatric disorder.

#### *Supporting the processing of pain related to loss*

Understanding of these complex areas in relation to people with PIMD is lacking. The dearth of resources and training mean that people with PIMD rarely access appropriate support, and parents, carers and professionals feel unqualified to approach such a sensitive issue (Ng et al, 2003;

McEvoy et al, 2010). Due to the difficulties in communication, traditional forms of intervention such as counselling have not been an option (Dowling et al, 2006). Bereavement resources and training have only recently been developed for people with PIMD (Phillip et al, 2005; Young et al, 2014b), but there is much needed research and practice to evaluate their use.

It is clear from the attachment literature that emotions can be socially regulated. A sensitive and responsive caregiver is characterised by their ability to be mindful of the other person's experiences, thoughts and feelings and seeks to meet their needs (Gold, 2011). Indications as to whether support is healing may be indicated by deep breathing and emotional sounds when breathing out, e.g. groaning or grunting, indicating activation of the parasympathetic nervous system (Rothschild, 2000). Clamminess, rapid breathing, jerkiness and emotional sounds when breathing in, suggests activation of the sympathetic nervous system and may indicate the person's difficulty with the support provided (the applications of physiological measurements of emotion in people with PIMD can be explored in Vos et al's (2010) work). Research and practice are now exploring the potential value of attachment-based perspectives for understanding and alleviating the challenges that people with ID face in their mental health (Schuengel et al, 2009). One practical suggestion which may support regulation is rhythmic movement, drumming, music and massage as inherently regulating activities (Perry et al, 2008).

### **Task Three: Adjusting to a world without the deceased**

#### *Lacking choice and control*

Death and loss can lead us to question the most basic assumptions that we make about predictability, security and safety. This may be particularly pertinent to people with PIMD, given the vulnerabilities they experience in relation to attachment relationships. The internal adjustments of which Worden (2008) describes, in order for healthy grieving, include assimilating to changes in relationships. The main barrier which may prevent people with PIMD from adapting to change is lack of choice and control. A study on happiness has suggested that those with PIMD have limited access to stimuli that is associated with happiness because of their difficulty in communicating their

preferences (Green et al, 1996). It was suggested that people with PIMD are particularly vulnerable to stress because of their inability to control their environment (Chaney, 1996; Phillip et al, 2005). Limited communication makes it difficult for the person to make known their wants and needs, and as such adjusting to a world without the deceased is challenging.

### *Supporting Adjustment*

Although very painful, an expected death may be easier to deal with than an unexpected one, because more time will allow less abrupt change and adjustment (Tuffrey-Wijne, 2013). Anticipated death can also allow the person time to prepare for the death (Raphael, 1984). Identifying the changes in routine and how to move smoothly through these transitions will help to minimise stress and upset. Preserving a familiar day-to-day routine will help to maintain a sense of safety and predictability. Where appropriate the carer may use communication aids to facilitate the person's ability to make choices (Goldbart et al, 2010).

### **Task Four: Find an enduring connection with the person who has died**

#### *Mobility and communicative limitations*

Worden (2008) emphasises the importance of continuing the relationship with the deceased in ways that are meaningful to the bereaved. Many people with PIMD experience a number of considerable mobility limitations (Cleaver et al, 2009). Those who do not have the physical ability to access sources of memories, such as photographs and videos, rely on others to facilitate this. They depend on sensitive others to do so, but this also involves that person identifying the most sensitive time to explore these, given that grief is thought to oscillate between loss and restoration tasks (Stroebe et al, 1999). Furthermore, our connections with people who have died are often relationally-based ones, facilitated by conversations and times of remembering the deceased with friends and family. Historically, the relationship narratives of people with ID have not been nurtured, meaning that their stories are often fragmented through loss and change (Atkinson et al, 1997). Difficulty communicating these narratives may make people with PIMD feel cut adrift, disconnected and misunderstood.

*Supporting connections with the person who has died*

In providing facilitation and intervention, it would be particularly beneficial for this group to engage with multi-sensory storytelling, creating artwork, memory boxes (Young et al 2011; Young et al, 2015) and life story work (Hewitt, 2000; Read et al, 2007a). For example, in a case study exploring the bereavement experience of a young woman with PIMD, Young et al (2015) demonstrated the use of a memory box as an important source of meaning around the loss. This supportive work as a means of fostering connection also concerns spirituality and ritual, which are not specific only to the task of enduring relationships, but are extremely relevant to connections that can be established at any point. The authors argue that the intellectual functioning of an individual is not an exclusive basis upon which to assess a person's ability, but that their spiritual experiences are also important (Meeusen-van de Kerkhof et al, 2013). Gaventa (2014) argues that each of us have a spiritual dimension and spiritual needs of people with PIMD must not be ignored (Swinton, 2002). For some people formal religion will be important. Religious rituals, stories and participation within an accepting community can be invaluable. For others, their spiritual needs might be met through their relationships, going to special places, encountering nature, music and art. All of these things can be important sources of meaning, hope, trust, value, identity and purpose. In fact, this is a crucial point upon which to end the main body of this text, for spirituality is an aspect that runs through all care and support with people with PIMD.

**Discussion**

It is argued that people with PIMD do not have the intellectual ability to understand complex concepts such as 'death' and 'dying'; that professionals lack the confidence, knowledge and skills required to explore these areas; and that a range of suitable resources do not exist to support such an exploration. Instead of including and supporting people with PIMD in the process of grieving, it is common for them to be excluded from this (Young et al, 2014a). Naturally, people with mild to moderate and severe ID may share some of the difficulties outlined in this paper. However, the severity of those difficulties, which characterise the group of people with PIMD, present unique

challenges, especially in relation to emotional and mental health issues. It is part of being human that we experience relationship *and* loss, but for people with PIMD, how much more difficult is this experience?

### ***Worden's model as a lens***

The present author suggests that cognitive approaches to the issue of bereavement in people with PIMD are restrictive in three ways. First, it neglects the significance of the person's historical narrative in relation to attachment relationships and what these have taught the person about love and loss, a subject which has been explored by Blackman (2003). Second, it abandons discussion around the important socio-cultural barriers which may prevent people with PIMD from engaging in the grieving process. Finally, from the claims that experience is dependant on intellectual disability, little is offered in terms of how we support bereaved people with profound cognitive impairments and communicative difficulties. While aspects of this framework has been subjected to a critical analysis, it nonetheless has highlighted an important element of bereavement and loss experience in people with PIMD that has been largely neglected. However, while the physical and cognitive impairments of people with PIMD are fixed, their experience of disability is not. In using Worden's (2008) model, it has diverted attention away from the impairment and has shifted focus on the barriers to the process of grieving, which have mainly arisen from lack of support and participation. One must not forget conversely, that although theories are valuable, we should continue to be guided by the bereaved individual.

### ***Supporting parents and professional carers***

Much of the literature on bereavement and people with ID has focussed primarily on the needs of the bereaved individual and very little attention has been given to the difficulties with which carers find providing support. Research has pointed to the challenges carers face in providing bereavement support: consent, confidence and guidance (Read, 2001; McHale et al, 2009). Moreover, training recommendations have included issues of complicated grieving and psychopathology (McHale et al, 2009; McEvoy et al, 2005). Recent research has highlighted the

emotional difficulty with which carers find exploring bereavement and loss issues with this group, particularly when they are grieving themselves (Handley et al, 2013). This is exacerbated by difficulties in understanding the grief reactions of people with intellectual disabilities, especially those that do not fit with expectations (e.g. delayed reactions, or not overt responses). Handley et al's (2013) study also reveals the importance of the carer having time to process the events before sharing news with the person. Carers may also be found remembering their own personal losses, which can affect their ability to explore these issues. Family carers and professional carers also articulate the uncertainty around offering bereavement support, when it leads to conflicting outcomes (i.e. for professional carers this involved intense support for one individual, disadvantaging others). The qualitative research strongly advocated for access to training for carers. The issues of staff confidence and knowledge is one that presents itself as a further barrier to grieving for the bereaved person and must be sensitively addressed.

### ***Future Research***

One must question the extent to which our current research and understanding has been affected by the barriers outlined in this conceptual paper. In other words, how can we fully understand the experience of bereavement in this group if we have not enabled them to engage with such an experience? Future research in this area is therefore warranted. It would also be interesting to evaluate the suggestions of support with empirical research. It is perhaps the case that the lack of research in this area has impeded practice and support for this group.

Overall, considerations of the bereavement experiences of people with PIMD require interpretation. It would be important to critically assess whether the cognitive approach is sufficient to describe their experiences. How much more difficult is it for people with PIMD to understand loss and what do their grief reactions tell us about their understanding? Furthermore, the question of whether bereavement research in mild to moderate and severe ID is applicable to people with PIMD is a crucial one. Research is yet to establish this.

### ***Conclusions***

The author has provided an assessment of the social, emotional and physical constraints that affect the extent to which people with PIMD engage with the tasks of grief, outlined by Worden (2008). These constraints range from barriers that are related to the views held by society, to barriers that are inherent in the disability of the individual. Suggestions of support include effective communication, listening and responding to upset and distress, providing opportunities to remember the person and encourage ways of maintaining the emotional bond with the deceased. In conclusion, bereavement support for people with PIMD benefits from consideration of socio-cultural barriers. While we cannot take the pain of the loss away, we can help to alleviate some of the barriers which prevent people with PIMD from grieving in supported ways.

#### References

Atkinson, D., Jackson, M. and Walmsley, J. (1997). *Forgotten lives*. Kidderminster: BILD Publications.

Blackman, N. 2003 *Loss and learning disability*. London: Worth Publishing.

Bowlby, J. 1980 *Loss: sadness and depression. Attachment and loss* (vol. 3). London: Hogarth Press.

Buntinx, W. 2008 The logic of relations and the logic of management. *Journal of Intellectual Disability Research* 52: 588–597.

Carnaby, S. 2004 *People with Profound and Multiple Learning Disabilities: A Review of Research about their Lives*. London: MENCAP.

Chaney, R.H. 1996 Psychological stress in people with profound mental retardation. *Journal of Intellectual Disability Research*. 40: 305–310.

Cleaver, S., Hunter, D. & Ouellette-Kuntz, H. (2009). Physical mobility limitations in adults with intellectual disabilities: a systematic review. *Journal of Intellectual Disability Research*, 53(2), 93-105.

Clegg, J. and Lansdall-Welfare, R. 2003 Death, Disability and Dogma. *Philosophy, Psychiatry and Psychology* 10: 67-79.

Codling, M. and MacDonald, N. 2009 Epilepsy: Implications for people with profound intellectual and multiple disabilities. In *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs* (Pawlyn, J. and Carnaby, S. eds.) Chichester: Wiley-Blackwell.

Colman, S. 2003 ‘What’s in the box then, Mum?’—Death, disability and dogma. *Philosophy, Psychiatry and Psychology* 10: 81-5.

Coupe O’Kane, J. and Goldbart, J. 1998 *Communication Before Speech*. London: David Fulton Publishers.

Dodd, P. and Blackman, N. 2014 Complicated grief. In *Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement: Theory and Compassionate Practice*. (Read, S. ed.) London: Jessica Kingsley Publishers.

Dodd, P. Dowling, S. and Hollins, S. 2005 A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. *Journal of Intellectual Disability Research* 49 (7): 537- 543.

Doka, K. 2002 *Disenfranchised Grief: New Directions, Challenges and Strategies for Practice*. Champaign, IL: Research Press.

Dosen, A. (2005). Applying the developmental perspective in the psychiatric assessment and diagnosis of persons with intellectual disability: part 2 – diagnosis. *Journal of Intellectual Disability Research* 49: 9-12.

Dowling, S. Hulbert, J. White, S. and Hollins, S. 2006 Bereaved adults with intellectual disabilities: A combined randomized controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research* 50 (4): 277-287.

Evenhuis, H. M. & Nagtzaam, L. M. D. (eds) 1998 *IASSID International consensus statement on early identification of hearing and visual impairment in children and adults with an intellectual disability*. IASSID Special Interest Research Group on Physical Health.

Forrester-Jones, R. 2013 The road barely taken: funerals, and people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 26: 243-256.

Gaventa, W. 2014 Spirituality and faith: Beyond beliefs to practice. In *Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement: Theory and Compassionate Practice*. (Read, S. ed.) London: Jessica Kingsley Publishers.

Gold, C. 2011 *Keeping Your Child in Mind*. New York: Dacapo Lifelong Books.

Goldbart, J. and Caton, S. 2010 *Communication and People with the Most Complex Needs: What Works and Why this is Essential*. London: Mencap & Department of Health.

Green, C.W. and Reid, D.H. 1996 Defining, validating, and increasing indices of happiness among people with profound multiple disabilities. *Journal of Applied Behavior Analysis* 29: 67–78.

Handley, E. and Hutchinson, N. 2013 The experience of carers in supporting people with intellectual disabilities through the process of bereavement: an interpretive phenomenological analysis. *Journal of Applied Research in Intellectual Disabilities* 26 (3):186-194.

Hewitt, H. 2000 A life story approach for people with profound learning disabilities. *British Journal of Nursing* 9 (2): 90-95.

Hogg, J. Juhlberg, K. and Lambe, L. 2006 Development and mortality over a 10-year period among people with profound intellectual & multiple disabilities. *Journal of Applied Research in Intellectual Disabilities* 19 (3): 262-262.

Janssen, C. G. C., Schuengel C. and Stolk J. 2002 Understanding challenging behaviour in people with severe and profound intellectual disability: a stress-attachment model. *Journal of Intellectual Disability Research*, 46, 445– 53.

Kelleher, A. and Mulcahy, M. 1986 Patterns of disability in the mentally handicapped. In J.M. Berg, (Ed.), *Science and Service in Mental Retardation. Proceedings of the Seventh Congress of the International Association for the Scientific Study of Mental Deficiency (IASSMD)*. London: Methuen.

Luchterhand, C. and Murphy, N. 1998 *Helping Adults with Mental Retardation Grieve a Loss*. London: Taylor and Francis.

Mansell, J. 2010 *Raising our Sights: Services for Adults with Profound and Multiple Learning Disabilities*. London: Department of Health.

McBride, E. and McDicken, A. 2012 Moving on: Facilitating the transition from child to adult services for young people with profound and multiple learning disabilities. *SLD Experience* 5: 27-31.

McEvoy, J. Guerin, S. Dodd, P. and Hillery, J. 2010 Supporting adults with an intellectual disability during experiences of loss and bereavement: staff views, experiences and suggestions for training. *Journal of Applied Research in Intellectual Disabilities* 23 (6): 585-596.

McEvoy, R. and Smith, E. 2005 Families perceptions of the grieving process and concept of death in individuals with intellectual disabilities. *The British Journal of Developmental Disabilities* 51(100): 17-25.

McHale, R. McEvoy, J. and Tierney, E. 2009 Caregiver perceptions of the understanding of death and need for bereavement support in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 22: 574-581.

Meeusen-van de Kerkhof, R. van Bommel, H. van de Wouw, W. and Maaskant, M. 2006 Perceptions of death and management of grief in people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities* 3 (2): 95-104.

Naber, F. B. A. Swinkels, S. H. N. Buitelaar, J. K. Bakermans-Kranenburg, M. J. Van Ijzendoorn, M. H. Dietz, C. Van Daalen, E. and Engeland, H. 2007 Attachment in toddlers with autism and other developmental disorders. *Journal of Autism and Developmental Disorders*, 37: 1123–1138.

Nakken, H. and Vlaskamp, C. 2002 Joining forces: Supporting individuals with profound multiple learning disabilities. *Tizard Learning Disability Review* 7: 10-15.

Ng, J. and Li, S. 2003 A survey exploring the educational needs of care practitioners in learning disability settings in relation to death, dying and people with learning disabilities. *European Journal of Cancer Care* 12 (1): 12-19.

Nind, M. and Hewett, D. 1994 *Access to Communication: Developing the Basics of Communication with People with Severe Learning Difficulties through Intensive Interaction*. London: David Fulton Publishers.

Oswin, M. 1991 *Am I allowed to cry? – A study of bereavement among people who have learning disabilities*. London UK: Souvenir Press.

Oxford Dictionary of English. 2015. 3rd ed. Oxford: Oxford University Press.

Parkes, C. M. 2006 *Love and Loss: The Roots of Grief and its Complications*. London: Routledge.

Patterson, R. and Hazlewood, M. 2014 'Dining with death' – Conversation menus as a means of educating people about death, dying and bereavement. *BMJ Supportive & Palliative Care* 4 (1): 177.

Pawlyn, J. and Carnaby, S. 2009 *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs*. Chichester: Wiley-Blackwell.

Perry, B.D. and Hambrick, E. 2008 Introduction to the neurosequential model of therapeutics. *The Journal of Strengths-based Interventions* 17: 38-43.

Phillip, M. Lambe, L. and Hogg, J. 2005 The well-being project: identifying and meeting the needs of young people with profound and multiple learning disabilities and their carers. In: *Making Us Count: Identifying and Improving Mental Health Support for Young People with Learning Disabilities* (ed J. Alcoe), pp. 111-130. London: Foundation for People with Learning Disabilities.

Piaget, J. 1954 *The construction of reality in the child*. New York: Basic Books.

Raphael, B. 1984 *The Anatomy of Bereavement*. London: Hutchinson & Co. Ltd.

Read, S. 2001 A year in the life of a bereavement counselling and support service for people with learning disabilities. *Journal of Learning Disabilities* 5 (1): 19-33.

Read, S. (ed.) 2014 *Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement: Theory and Compassionate Practice*. London: Jessica Kingsley Publishers.

Read, S.C. and Bowler, C. 2007a Life story work and bereavement: shared reflections on its usefulness. *Learning Disability Practice*, 10 (4): 10-15.

Read, S. and Elliott, D. 2007b Exploring a continuum of support for bereaved people with intellectual disabilities: a strategic approach. *Journal of Intellectual Disabilities* 11 (2): 167-181.

Rothschild, B. 2000 *The Body Remembers: The Psychophysiology of Trauma and Trauma Treatment*. New York: W.W. Norton.

Schore, A.N. 2001. Effects of a secure attachment relationship on right brain development, affect regulation, and infant mental health. *Infant Mental Health Journal*, 22 (1-2): 7-66.

Schuengel, C. Sterkenburg, P.S. Jeczynski, P. Janssen, C.G. and Jongbloed, G. 2009. Supporting affect regulation in children with multiple disabilities during psychotherapy: a multiple case design study of therapeutic attachment. *Journal of Consulting and Clinical Psychology* 77 (2): 291-301.

Sheehy, K. and Nind, M. 2005 Emotional well-being for all: mental health and people with profound and multiple learning disabilities. *British Journal of Learning Disabilities* 33 (1): 34-38.

Sinason, V. 1986 Secondary mental handicap and its relationship to trauma. *Psychoanalytic Psychotherapy*, 2 (2): 131-154.

Simmons, B. and Watson, D. 2014 *The PMLD Ambiguity: Articulating the Life-Worlds of Children with Profound and Multiple Learning Disabilities*. London: Karnac.

Sorce, J. F. Emde, R. N. Campos, J. and Klinnert, M. D. 1985 Maternal Emotional Signaling: Its Effect on the Visual Cliff Behavior of 1-year-olds. *Developmental Psychology* 21 (1): 195-200.

Sormanti, M. and Ballan, M. 2011 Strengthening grief support for children with developmental disabilities. *School Psychology International* 32: 179-193.

Stroebe, M. and Schut, H. 1999 The dual process model of coping with bereavement: rationale and description. *Death Studies* 23 (3): 197-224.

Stoddart, K.P. Burke, L. and Temple, V. 2002 Outcome evaluation of bereavement groups for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 15: 28-35.

Swinton, J. 2002 Spirituality and the lives of people with learning disabilities. *Tizard Learning Disability Review* 7 (4): 29-35.

Tang, J. Patterson, T.G. Kennedy, C.H. 2003 *Identifying specific sensory modalities maintaining the stereotypy of students with profound multiple disabilities*. *Research in Developmental Disabilities* 24: 433-451.

Trevarthen, C. and Aitken, K. J. 2001 Infant intersubjectivity: Research, theory, and clinical applications. *Annual Research Review. The Journal of Child Psychology and Psychiatry and Allied Disciplines* 42 (1): 3-48.

Tuffrey-Wijne, I. 2013 *How to Break Bad News: To People with Learning Disabilities*. London: Jessica Kingsley Publishers.

Vos, P. De Cock, P. Petry, K. Van Den Noortgate, W. and Maes, B. 2010. Do you know what I feel? Towards a physiological measure of the subjective well-being of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities* 23: 366-378.

Wallis, C. 2009 Respiratory health of people with profound intellectual and multiple disabilities. In *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs* (Pawlyn, J. and Carnaby, S. eds.) Chichester: Wiley-Blackwell.

Ware, J. 2003 *Creating Responsive Environments for People with Profound and Multiple Learning Difficulties* (2nd Edition). London: David Fulton Publishers.

Weeks, O.D. 2004 Comfort and healing: death ceremonies that work. *Illness, Crises & Loss* 12 (2): 113-125.

Wiese, M. Dew, A. Stancliffe, R.J. Howarth, G. and Balandin, S. 2013. 'If and when?': the beliefs and experiences of community living staff in supporting older people with intellectual disability to know about dying. *Journal of Intellectual Disability Research* 57 (10): 980-992.

Worden, J.W. 2008 *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner* (4th edition). New York: Springer.

Young, H. Fenwick, M. Lambe, L. and Hogg, J. 2011 Multi-sensory storytelling as an aid to assisting people with profound intellectual disabilities to cope with sensitive issues: a multiple research methods analysis of engagement and outcomes. *European Journal of Special Needs Education* 26 (2): 127-142.

Young, H. Garrard, B. Lambe, L. and Hogg, J. 2014a Helping people cope with bereavement. *Learning Disability Practice* 17 (6): 16-20.

Young, H. Garrard, B. and Lambe, L. 2014b *Supporting Bereaved People with Profound and Multiple Learning Disabilities and their Parents and Carers*. Dundee, Scotland: PAMIS.

Young, H. and Garrard, B. 2015 Bereavement and loss: Developing a memory box to explore bereavement and loss with a young woman with profound learning disabilities. *British Journal of Learning Disabilities*. DOI: 10.1111/bld.12129