



**University of Dundee**

## **Conceptualising bereavement in profound and multiple learning disabilities**

Young, Hannah

*Published in:*  
Tizard Learning Disability Review

*DOI:*  
[10.1108/TLDR-09-2015-0035](https://doi.org/10.1108/TLDR-09-2015-0035)

*Publication date:*  
2016

*Document Version*  
Peer reviewed version

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

*Citation for published version (APA):*  
Young, H. (2016). Conceptualising bereavement in profound and multiple learning disabilities. *Tizard Learning Disability Review*, 21(4), 186-198. <https://doi.org/10.1108/TLDR-09-2015-0035>

### **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.

## Abstract

*Purpose* Bereavement and loss are key factors in poor emotional wellbeing among people with profound and multiple learning disabilities. However, little attention has been drawn to this in the grief and disability literature. This paper aimed to make sense of bereavement and loss in this group, with reference to theoretical contributions to the field and studies of grief reactions.

*Design/Methodology/Approach* A systematic review revealed thirty-four relevant published works. These were analysed for relevant contributions, and then subjected to peer-review. *Findings* Three main types of theoretical contributions have been made; traditional grief theories, cognitive approaches and attachment-based perspectives. Although a limited number of case studies exist, a range of grief reactions have been reported in people with profound and multiple learning disabilities. Traditional grief theories and cognitive approaches are somewhat limited in making sense of grief responses in this group, while attachment-based perspectives may prove useful in providing theoretical and practical direction. *Research Implications* Further research is required to more accurately describe the nature of relationships in people with PMLD. *Practical Implications* Major contributions to the field point to the value of facilitating engagement with the grieving process, through communication around the loss and training for staff. In addition, attachment-based perspectives are offering routes for establishing therapeutic relationships that help to resolve behavioural difficulties. *Originality/value* This paper provides an overview of the perspectives within bereavement and disability, drawing together clear theoretical frameworks for future research and practice.

Keywords: profound and multiple learning disabilities, grief, attachment, mental health, behaviour, theory

### Conceptualising bereavement in profound and multiple learning disabilities

Bereavement and loss are experiences that impact on all persons. Complicating these experiences, however, are the psychological vulnerabilities of people with learning disabilities (LDs) (Read, 2014). Among people with profound and multiple learning disabilities (PMLDs), loss is a key factor in poor emotional wellbeing (Phillip et al., 2005), but studies of loss experiences and grief reactions (Dodd et al., 2005) have drawn little attention to this group. Oswin (1985) is perhaps the first to explicitly distinguish between people with PMLD and those more able in terms of their experience of loss. She attributes this difference to significant sensory impairments, which impact on the developing concept of death. Related to this, the expression of internal states and communication of grief can be obstructed by lack of physical mobility. Neglect of those presenting as intellectually less able prevents the researcher and practitioner from providing informed perspectives to approaches in therapeutic work.

#### *Significant needs of people with profound and multiple learning disabilities*

How we define PMLD is of great significance for how grief is conceptualised in this group. Within the international literature, people with PMLD are also referred to by: ‘profound intellectual and multiple disabilities’, ‘profound mental retardation’, ‘multiple handicaps’ and in some cases ‘severe learning disabilities’ (Nakken and Vlaskamp, 2002). Their condition is multifaceted, characterised mainly by their physical and sensory impairments against many health-related problems (Pawlyn and Carnaby, 2008). In addition, the most severe form of intellectual impairment (i.e. an IQ below 20) is thought to represent their cognitive status (Mansell, 2010); functioning at early stages of development (Coupe O’Kane and Goldbart, 1998).

#### *Aims of the review*

Overall, the literature has scarcely provided consideration of the above difficulties experienced by people with PMLD, and how these may shape the experience of bereavement and loss. Conversely, it has afforded a variety of approaches to understanding grief in people with LD

more generally, which may bear relevance to this complex area. We return to this point in the discussion section. Meanwhile, the following questions guide the systematic review:

1. What have been the theoretical contributions to the area of bereavement, loss and LD?
2. What are the grief reactions of people with PMLD?

#### Method

Using the PRISMA guidelines (Moher et al., 2009), the author carried out a systematic review of the literature. Databases used included ASSIA, CINAHL, ERIC, PubMed, PubPsych and Scopus, using the following search terms, relating to the research questions above:

1. “(bereavement OR loss OR grief) AND ((learning OR intellectual OR mental OR multiple) AND (disabilit\* OR mental retardation)) AND (theory OR framework OR model)”.
2. “(bereavement OR loss OR grief) AND (((((learning OR intellectual OR mental OR multiple) AND disabilit\* OR mental retardation)) AND (severe OR profound)))”

The literature review was conducted in 2015, and no start dates were specified in the search criteria. Only English-language material was included. A manual search was also carried out in the PAMIS Library; hand searches included relevant journals, published books and previous literature reviews. A snowballing method was also used whereby literature was searched for relevant references.

All records emerging from the two search terms were combined, which provided both a theoretical overview and a specific focus on the profound group, with some papers bearing relevance to both these topics. Titles and abstracts were then screened for relevance to the research questions (see Figure 1). Each full-text was then included on the basis that it met the following criteria:

1. explicitly driven or explained by theory, models and conceptual frameworks (e.g. established theories in psychology or systems models), or contributes a new approach.

AND/OR

2. involved people with PMLD as participants, or draws conclusions regarding this group from a review of the literature. Note: 'severe' was included in the search engine terms in order to identify those groups who can be defined as PMLD given information on their cognitive functioning and health status
3. reports experiences of bereavement and loss or describes grief reactions of people with PMLD

Inclusion criteria were tested for validity by a second researcher, by checking that included papers fit the criteria outlined. Extrapolation of final results were also subjected to peer-review by the second researcher, using Table 1 as a basis for comparing interpretations. These processes were conducted systematically through each included paper. Disagreements led to discussions about clarity of the inclusion criteria and relevance of the included papers. This led to refinement of the stated criteria and some papers were excluded due to their limited relevance.

[Insert Figure 1 here]

## Results

The current research questions are addressed directly by the reviewed literature, below. In Part I, the review compares and contrasts a variety of theoretical contributions to the field (see Table 1). Part II provides an overview of case studies that illustrate grief reactions in people with PMLD (Table 2).

*Part I: Theoretical contributions to the understanding of bereavement and loss in people with learning disabilities*

### *Traditional theories of grief*

As succinctly presented in Read's (2014) chapter, grief has mainly been conceptualised in terms of task, stage and phase models of grief, and this is largely reflective of the literature reviewed here. For example, we find that Oswin (1991) is influenced by the universal approach to grief, in which mourning is thought to eventually reach resolve. Her view that people with LDs

grieve in much the same way as non-learning disabled people led her to strongly advocate for their inclusion in grieving rituals. Subsequent contributions can be found extending this approach. One of the strongest examples can be found in Stoddart and McDonnell's (1999) paper in which resolution of grief is the desired outcome of a systems-based intervention. This grief-work approach is also reflected in Barber (2012) and Conboy-Hill (2002), where the authors seek to establish the relevance of Kübler-Ross' (1969) five stages of bereavement, although both acknowledge the need for more contemporary models with clear theoretical underpinnings.

In addition, many research practitioners have offered a variety of practical suggestions for support, including life-story work and multi-sensory methods for engaging in the grieving process. Luchterhand and Murphy (1998), Young et al., (2014b) and Young and Garrard (2015) use Worden's four tasks of grief (1982; 1991) to inform intervention in similar ways. For example, the person's lack of mobility may make it difficult for them to access physical memories and therefore connect with the deceased. Providing the person with opportunities to remember using photographs and videos is one suggested way of overcoming the barrier of physical disability and facilitate connection with the person who has died. Although a relatively recent area, bereavement research and practice in the LD field has mainly been preoccupied with the grief-work approach.

#### *Attachment and people with learning disabilities*

Attachment theory has attained significance in providing a useful therapeutic approach to the field (Blackman, 2011). This work has revealed a number of factors that can complicate the grieving process, which are discussed more fully below. Research practitioners are now asking questions about the nature of attachments in people with LDs and how these bonds change over time, following loss. Referring to Klass *et al's* (1996) *Continuing Bonds*, Blackman (2003) describes grief as multi-dimensional and partly understood in terms of how the individual maintains the connection with the deceased person. These considerations have led to a number of suggestions for support. For example, by integrating the principles of attachment (Klein, 1940; Bowlby, 1981) and bereavement theory (Freud, 1917; Parkes, 1996), Summers and Witts (2003) provide a

theoretical framework for understanding grief and loss for Joanne, a woman with moderate to severe LD following the death of her father. Her experiences of early abuse and insecure attachment relationships led to a number of hypotheses regarding her experience of bereavement, including complicated grieving. Use of psycho-educational and psycho-dynamic approaches were effective interventions within this therapeutic context, and is also reflected in the work of Sinason (1992) and Blackman (2011).

Focusing more widely on the issues of research, assessment and intervention, Schuengel et al (2013) explore the potential of attachment-based perspectives (Bowlby, 1984) in understanding mental health. The authors emphasise the importance of assessing the attachment bond in determining the experience of separation distress. Support for this approach can be found in studies describing successful and effective therapy for attachment and behaviour (Sterkenburg et al., 2008). Their main postulation being that if the caring other provides a secure base, the individual can cope better with loss and other difficult experiences.

#### *Cognitive theory and developmental approaches*

It is not surprising, given that LD is commonly defined in terms of intellectual functioning, that cognitive approaches make a significant contribution to the grief literature. Researchers in this area have focussed on the cognitive capacities of individuals with LD to form realistic concepts of death. In a conceptual paper, Meeusen-van de Kerkhof et al (2006) draw mainly on Piaget's (1954) theory of cognitive development to frame the bereavement experiences of people with varying levels of LD. For example, it is suggested that people with PMLD experience loss as a 'breach of fixed patterns', and do not have a concept of death. This has clear applications for practice; the authors stress the importance of maintaining routine and allowing the bereaved to touch the dead person. This is contrasted for people with mild LD (IQ 50-70) who can hold more abstract concepts of death and follow a similar mourning process to those without LD. When considering the literature in its entirety, there is a clear overemphasis on cognitive approaches to conceptualising loss in people with LDs generally.

*Complicated grieving*

Traditional grief theory, attachment theory and cognitive approaches to bereavement can be found intersecting at the discourse of complicated grieving. One perspective is that people with LDs require enablement to engage with tasks of grieving in order to experience resolution or adaptation. It may also be argued that separation distress is at the core of difficulties in grieving and that attachment relationships are key to supporting the individual. A cognitive perspective argues that confusion around or misunderstanding of the concept of death can exacerbate and prolong grief. More recently, there has been an emergence of literature exploring the risk factors for complicated grieving, drawing partly on both of these ideas, to suggest that bereavement and loss can be traumatic experiences for those who are susceptible to psychological destabilisation, are less able to process memory and struggle to integrate experience into their personal narratives.

Historically, authors have outlined the risk factors for complicated grieving in this group. Dodd et al (2009; 2014) is perhaps the main proponent of this approach, in which risk factors have been identified: dependency, insecure attachments, social isolation and secondary losses. This literature elegantly frames a number of issues that complicate the grieving process for people with LD, and have been discussed in Read and Elliot's (2003) 'vulnerability perspective'. Here, the challenges that care staff experience in relation to offering bereavement support, protection from the truth, and limited understanding are identified as key issues that render bereaved individuals with LD vulnerable to the effects of loss (Read and Elliot, 2003).

[Insert Table 1 here]

**Part II: Reported grief reactions in people with profound and multiple learning disabilities**

Focusing now on the second research question of this review, nine published works report on the responses to bereavement and loss in people with PMLD (Table 2). All works were descriptive, adopting case study methodology (N=4), interviews with parents and carers (N=4), and reference to research (N=2).



Experiences of loss included staff turn-over and loss through the death of loved ones. In particular, Sinason's (1992) psychoanalytic work in a residential centre revealed the impact of staff-turnover on four individuals with PMLD. Against this backdrop, there are a number of experiences involving change, including transition and health-related problems. In addition, at least two individuals had experienced interpersonal trauma due to abandonment in their early years.

A range of grief responses can be found in the case study illustrations, but the attachment behaviours may be particularly significant; there is some disagreement between the works about the presence of grief reactions among this group. For instance, Meeusen-van de Kerkhof *et al* (2006) state that people with PMLD do not exhibit grief responses through crying, although this is reported in five separate cases of the review. However, Meeusen-van de Kerkhof *et al* (2006) may be referring to 'crying' behaviour that has a "mourning function", rather than the calling behaviours of early separation responses that seek to attract the caregiver to the distressed child. There is insufficient data to make any inferences about the distinction here, but there are a number of cases identified in this review with clear searching, calling and clinging behaviour.

In each of the case illustrations, there were significant changes in behaviour, with challenging behaviour and self-injury present in the majority of the studies. Delayed grief could perhaps be identified in Tuffrey-Wijne's (2013) case study and long-term grief reactions (i.e. longer than 12 months) identified in two cases. Oswin (1985) reported loss of some abilities. This was not overtly identified in any of the other texts, but could be otherwise indicated by withdrawal and loss of appetite. Due to limitations in verbal communication within this group, it would not be possible to assess understanding.

[Insert Table 2 here]

## Discussion

What sense can we make of the grief reactions of people with PMLD, in light of theoretical contributions outlined in this paper? Although many of the works did not explicitly take account of

this group, we can perhaps extrapolate their main points and apply them to the profound group.

These contributions may also shed some light on understanding their grief reactions.

#### *A grief-work approach*

Overall, the majority of the literature can be found relying on traditional grief theory (e.g. Parkes, 1972; Kübler-Ross, 1970; Worden, 2008), adopting a ‘challenges vs facilitation’ approach to the complexities that intellectual impairments present. The grief-work approach would suggest that people with PMLD may experience the most difficulty in engaging with the grieving process and would therefore benefit from support that enables them to overcome these barriers. It is worth considering, however, “...the multiplicity of possible responses to bereavement...” (Clegg & Lansdall-Welfare, 2003, p. 69), which runs counter to the universal stage theories of grief. Despite a number of additional contributions that have acknowledged the limitations of perceiving grief in this universal way, it nonetheless has shaped much of the guidance around intervention.

Of course, we must be careful in assessing the appropriateness of any approach on a case-by-case basis. In addition, some suggestions of this approach (e.g. death education, group work) may be seen as inappropriate or unreachable for the PMLD group, although work using creative arts and multi-sensory methods have demonstrated the value of alternative communication around bereavement and loss (Young et al., 2015). Therefore, the field would benefit from continued research into how we may facilitate the engagement of people with PMLD, in relation to sensitive issues.

#### *Severe cognitive impairments*

Whilst the traditional grief theories would suggest that people of all levels of cognitive functioning grieve in the same way, this can be contrasted with the cognitive and developmental approaches, which advocate that grieving differs between these groups. Very little of the conceptual literature has drawn any relevance to people with PMLD, with the exception of Meeusen-van de Kerkhof *et al*'s work (2006), which presents the most striking presentation of the cognitive approach. Their framework suggests that people with PMLD simply experience

bereavement and loss as a mismatch between familiar patterns and the reality of the loss. This approach to people with PMLD reflects the once common view that people with LDs do not have the capacity to understand death and therefore have no grief response. It is clear that from the literature reviewed here, this suggestion has been challenged by the case illustrations reviewed in this paper as they demonstrate the psychological and physical expressions of grief in people with PMLD. Moreover, the cognitive approach offers little in terms of bereavement support for this group. It would be beneficial for this area to provide an account of how their conceptualisations lead to their proposed interventions. For example, how does touching a dead body provide counselling to people with PMLD, or what is the function of this in light of a cognitive approach that suggests no concept of death?

#### *Insecure attachment relationships as a risk factor for complicated grieving*

The current review points to one area of significant interest that is founded upon a strong evidence base. This empirical research directs us to the value of attachment-based perspectives in both understanding the experience of bereavement and guiding support for people with PMLD. There is a body of work in the LD field, which supports the use of relationship building that supports regulation of difficult emotions (Schuengel et al., 2013). Certainly, these approaches are making some way to guiding strong evidence-based interventions in this area. The latter is a long way from investigating this in people with PMLD, however, but future research may provide a better understanding of attachment relationships in this group, and related risk factors for complicated grieving. Indeed, in supporting the attachment-based perspective, Dodd et al (2005) call for the field to move beyond seeing bereavement as requiring intervention and instead working towards developing and supporting relationships. Future research in this area may seek to better understand the separation behaviours of people with PMLD, and fully consider those factors contributing to complicated grieving in this group.

#### *Conclusions*

The literature, at present, offers no great deal of insight into the experience of or reactions to loss in people with PMLD. Mainly, the responses of people with PMLD would suggest that they do respond to bereavement and loss, but that the nature of this experience is a matter of discussion for theoretical discourse. Both traditional theory and cognitive approaches are limited in demonstrating their contribution to this discussion. It is suggested, however, that although research is in its infancy, we may find that adding the attachment-based perspective to this discussion will provide an alternative viewpoint from which to propose effective and sensitive support for those with the most severe and complex needs.

### References

Barber, C. (2012), "Death, dying, bereavement and people with a learning disability (1/2)", *British Journal of Healthcare Assistants*, Vol. 6 No. 2, pp. 24-27.

Blackman, N. (2002), "Grief and intellectual disability: A systemic approach", *Journal of Gerontological Social Work*, Vol. 38 No 1, pp. 253-261.

Blackman, N. (2003), *Loss and Learning Disability*, Worth Publishing, London.

Blackman, N. (2008), "The development of an assessment tool for the bereavement needs of people with learning disabilities", *British Journal of Learning Disabilities*, Vol. 36, pp. 165–170.

Blackman, N. (2011), "The Use of Psychotherapy in Supporting People with Intellectual Disabilities who Have Experienced Bereavement", PhD Thesis. University of Hertfordshire, UK.

Bowlby, J. (1960), "Grief and mourning in infancy and early childhood", *Psychoanalytic Study of the Child*, Vol. 15, pp. 9-52.

Bowlby, J. (1973), *Attachment and Loss: Volume 2: Separation, Anxiety and Anger*, Penguin Books, St Ives, UK.

Bowlby, J. (1980; 1981), *Attachment and Loss: Volume 3: Loss, Sadness, and Depression*, Basic Books, New York.

Bowlby, J. (1984), *Attachment and Loss: Volume 1: Attachment*, Penguin, London.

Brown, E. (1999), *Loss, Change and Grief: An Educational Perspective*, David Fulton Publishers, London.

Clegg, J. and Lansdall-Welfare, R. (2003), "Death, Disability and Dogma", *Philosophy, Psychiatry and Psychology*, Vol. 10, pp. 67-79.

Clements, P.T., Focht-New, G. and Faulkner M.J. (2004), "Grief in the shadows: Exploring loss and bereavement in people with developmental disabilities", *Issues in Mental Health Nursing*, Vol. 25, pp. 799-808.

Conboy-Hill, S. (1992), "Grief, loss and people with learning disabilities", in Conboy-Hill, S and Waitman, A. (Eds.), *Psychotherapy and Mental Handicapp*, Sage, London, pp. 150-170.

Coupe O’Kane, J. and Goldbart, J. (1998), “Communication Before Speech”, David Fulton Publishers, London.

Crane, J. (2005), “The Effects of Bereavement and Loss on Pupils with Severe Learning Difficulties” [article],

Retrieved from: [http://www.buckscc.gov.uk/media/136355/research\\_bereavement.pdf](http://www.buckscc.gov.uk/media/136355/research_bereavement.pdf)

Danziger, K. (1997), “The varieties of social construction”, *Theory & Psychology*, Vol. 7, pp. 399–416.

Dodd, P. and Blackman, N. (2014) “Complicated grief”, in Read, S. (Ed.), *Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement: Theory and Compassionate Practice*, Jessica Kingsley Publishers, London, pp. 59-70.

Dodd, P., Dowling, S. and Hollins, S. (2005), “A review of the emotional, psychological, and behavioral responses to bereavement in people with intellectual disabilities”, *Journal of Intellectual Disability Research*, Vol. 49, pp. 537-543.

Dodd, P. and Guerin, S. (2009), “Grief and bereavement in people with intellectual disabilities”, *Current Opinion in Psychiatry*, Vol. 22 No. 5, pp. 442-446.

Doka, K. (2002), *Disenfranchised grief: New directions, challenges, and strategies for practice*, Research Press, Champaign, IL.

Dowling, S., Hubert, J. and Hollins, S. (2003), “Bereavement interventions for people with learning disabilities: 'my mother's name was Marjorie' ”, *Bereavement Care*, Vol. 22, pp. 19-21.

Elliot, D. (1996), "Learning Disabilities: A practical approach to helping people to grieve", *British Journal of Community Health Nursing*, Vol. 1, pp. 209-213.

Fowler, J. W. (1981). *Stages of Faith: The Psychology of Human Development and the Quest for Meaning*. Harper, San Francisco, CA.

Freud, S. (1957), "Mourning and melancholia", in: Strachey, J. (Ed.), *The Standard Edition of the Complete Psychological Works of Sigmund Freud*, Hogarth/Institute of Psychoanalysis, London, pp 197- 205.

Harper, D.C. and Wadsworth, J.S. (1993), "Grief in adults with mental retardation: Preliminary findings. *Research in Developmental Disabilities*", Vol. 14, pp. 313-330.

Heron, J. (1989), *The facilitators' handbook*, Kogan Page Limited, London.

Hinton, J. (1967), *Dying*, Pelican, Harmondsworth.

Klass, D. , Silverman, P.R. and Nickman, S.L. (1996), *Continuing bonds, new understandings of grief*, Taylor and Francis, Philadelphia, USA.

Klein, M. (1940), "Mourning and its relation to manic-depressive states", *International Journal of Psychoanalysis*, Vol. 21, pp. 311-338.

Kübler-Ross, E. (1969; 1970), *On Death and Dying*. Londond: Tavistock.

Kübler-Ross, E. (1981), *Living with Death and Dying*, Macmillan, New York.

Lindemann, E. (1944), "The symptomatology and management of acute grief", *American Journal of Psychiatry*, Vol. 101, pp. 141-148.

Luchterhand, C. and Murphy, N. E. (1998), "Helping adults with mental retardation grieve a death loss", Taylor & Francis, Philadelphia.

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

McEvoy, J., Machale, R. and Tierney, E. (2012), "Concept of death and perceptions of bereavement in adults with intellectual disabilities", *Journal of Intellectual Disability Research*, Vol. 56, pp. 191-203.

McLoughlin, I.J. (1987), "A case of affective psychosis following bereavement in a mentally handicapped woman", *British Journal of Psychiatry*, Vol. 151, pp. 552-554.

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 disabilities", *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 3, pp. 95-104.

Moddia, B. and Chung, M.C. (1995), "Grief reactions and learning disabilities", *Nursing Standard*, Vol. 9, pp. 38-39.



Moher, D., Liberati, A., Tetzlaff, J. and Altman, D.G. (2009), "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement", *BMJ* 2009;339:b2535, doi: 10.1136/bmj.b2535

Murgatoyd, S. (1985), "Counselling and helping", Methuen/BPS, London.

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

Oswin, M. (1985), "Bereavement", in Craft, M, Bicknell, J and Hollins, S. (Eds. ), *A Multi-Disciplinary Approach to Mental Handicap*, Bailliere Tindal, London, pp. 197-205.

Oswin, M. (1989), "Bereavement and mentally handicapped people", in Philpot, T. (Ed.), *Last Things: Social Work with the Dying and Bereaved*, Reed Business Publishing, Wallington, pp. 95-108.

Oswin, M. (1991), *Am I Allowed to Cry? A study of bereavement amongst people who have learning difficulties*, Human Horizons, London.

Parkes, C. M. (1964), "Recent bereavement as a cause of mental illness", *British Journal of Psychiatry*, Vol. 110, pp. 198-204.

Parkes, C.M. (1972; 1996), *Bereavement: Studies of Grief in Adult Life*, Routledge, London.

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

Payne, S., Horn, S. and Relf, M. (1999), *Loss and Bereavement*, Open University Press, Buckingham.

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 Alcoe, J. (Ed.), *Making Us Count: Identifying and Improving Mental Health Support for Young People with Learning Disabilities*, Foundation for People with Learning Disabilities, London, pp. 111-130.

Piaget, J. (1954), *The Construction of Reality in the Child*, Basic Books, New York.

Piaget, J. (1960), *The Psychology of Intelligence*, Routledge and Keegan Paul, London.

Prigerson, H.G., Shear, M.K., Jacobs, S.C. et al. (1999), "Consensus criteria for traumatic grief: A preliminary empirical test", *British Journal of Psychiatry*, Vol. 174, pp. 67-74.

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

Read, S. and Bowler, C. (2007), "Life story work and bereavement: Shared reflections on its usefulness". *Learning Disability Practice*, Vol. 10 No. 4, pp. 10-14.

Read, S. and Elliot, D. (2007), "Death and learning disability: A vulnerability perspective", *The Journal of Adult Protection*, Vol. 5 No. 1, pp. 5-14.

Shuchter, S.R. and Zisook, S. (1993), "The course of normal grief", in Stroebe, W and Hansson, R.O. (Eds.), *Handbook of Bereavement*, Cambridge University Press, Cambridge, UK, pp 23-44.

Schuengel, C. , Clasien de Schipper, J. , Sterkenburg, P.S. and Kef, S. (2013), "Attachment, intellectual disabilities and mental health: research, assessment and intervention". *Journal of Applied Research in Intellectual Disability*, Vol. 26, pp. 34-46.

Sinason, V. (1992), *Mental Handicap and the Human Condition*, Free Association Books, London.

Sormanti, M., and Ballan, M. (2011), "Strengthening grief support for children with developmental disabilities". *School Psychology International*, Vol. 32, pp. 179-193.

Sterkenburg, P.S. , Janssen, C.G.C. and Schuengel, C. (2008), "The effect of an attachment-based behaviour therapy for children with visual and severe intellectual disabilities". *Journal of Applied Research in Intellectual Disabilities*, Vol. 21, pp. 126-135.

Stoddart, K. & McDonnell. (1999), "Addressing grief and loss in adults with developmental disabilities", *Journal on Developmental Disabilities*, Vol. 6 No. 2, pp 51-65.

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*, Vol. 15, pp. 28-35.

Stroebe, M. & Schut, M. (1999), "The dual process model of coping with bereavement: Rationale and description", *Death Studies*, Vol. 23 No 3, pp 197-224.

Summers, S.J. and Witts, P. (2003), "Psychological interventions for people with learning disabilities who have experienced bereavement: a case study illustration". *British Journal of Learning Disabilities*, Vol. 31, pp. 37-41.

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*, Vol. 24, pp. 433-451.

Timmers-Huigens, D. (1998), *Mogelijkheden voor verstandelijk gehandicapten*, Elzevier/De Tijdstroom, Maarssen, the Netherlands.

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

Wolfensberger, W. (1972), *The Principle of Normalization in Human Services*, National Institute on Mental Retardation, Toronto.

Worden, J. W. (1982; 1983; 1991; 2008), *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner*, Springer Publishing Co, New York.

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

Young, H. , Garrard, B. and Lambe, L. (2014b), "Supporting bereaved people with profound and multiple learning disabilities and their parents and carers", PAMIS, Dundee.

Young, H. and Garrard, B. (2015), "Bereavement and loss: developing a memory box to support a young woman with profound learning disabilities". *British Journal of Learning Disabilities*, Vol. 44, pp. 78-84.