UK childhood bereavement services: A reflection on their development and cultural influence

Liz Rolls, MA, PhD. MBACP (Accred)
Honorary Research Fellow, School of Health and Social Sciences,
University of Gloucestershire
Tutor, EMDR Practitioner, Gloucestershire Counselling Service, Stroud.
Gloucestershire
lrolls@glos.ac.uk

Abstract: Childhood bereavement services are a relatively recent form of child welfare provision in the UK. They are predicated on assumptions about the development of children and on an increasing research base that describes the potential impact of childhood bereavement and that support following bereavement is beneficial. UK services largely began as a result of practitioners responding to the needs of bereaved children. Over time, services have become more formalised into an organisational framework, contributing to and influenced by practice based experience, research and training. They have become more sophisticated and wide-ranging in their response to the needs of bereaved children for which there is evidence of a favourable impact on their wellbeing. More importantly, as a structural form of provision now embedded within the UK's health and social landscape, childhood bereavement services have had a significant impact on social policy and the wider cultural discourse concerning bereaved children.

Keywords: Childhood bereavement services, childhood bereavement, service development, impact, culture

Introduction

This paper is a reflection on the development and influence of childhood bereavement services as a specific form of child welfare provision in the UK.[1] Rather than providing a definitive history of services or a comprehensive review of childhood bereavement, it locates this form of provision within the context of *assumptions* about: the development of children; whether bereavement in childhood has an impact on them and the nature of that impact; and whether support for children following bereavement is beneficial. It describes the early days of service growth from the realm of an individual practitioner's response to a bereaved child to the embedded structural form that these services now occupy within the UK's health and social landscape. It then outlines three challenges that services currently face, before considering their impact on the wellbeing of bereaved children and their contribution to the wider cultural discourse concerning them.

Theoretical perspectives on childhood, children's development and childhood bereavement

Childhood and children's development

Although we have all been children, it cannot be taken for granted that we understand more broadly the 'condition of childhood'. Notions of 'children' and 'childhood' can be understood from a number of competing perspectives. Ariés (1962), who offers one of the earliest historical perspectives on our understanding, argued that the gradual separation of children – in Western Europe at least – into a discreet category of 'childhood' went through a series of historic progressions in which broader *institutional changes* had an impact on a number of groups, including children, with modern society now providing 'each way of life with a confined space in which it [is] understood that the dominant

---

[1] For ease of reading, the terms child, children and childhood are used throughout the paper to refer to both children and young people.

© 2019 Cruse Bereavement Care DOI: 10.1080/02682621.2019.1679483

features should be respected, and that each person [has] to resemble a conventional model, an ideal type' (Ariés, 1962, p. 415, quoted in Corsaro, 1997, p. 51). This demarcation of childhood from adulthood has enabled the development of the field of child psychology, itself further accentuating this demarcation (Corsaro, 1997; Foley, 2001; Rolls & Payne, 2004).

Children's development and socialisation has largely been studied in the psychological domain (Mayall, 1999) through which they have been 'observed' as passive, leading to the 'construction of a linear, sequential and normalised process by which children become adults' (Alldred, 1998, p. 150), and a form of socialisation of children that involves training children to *become* competent adult members of society. This future-orientated model (Lee, 2001) places child development as a forward-linear process directed towards adulthood through a period of 'adolescence', a recent invention whose boundaries or contours are uncertain (Buckingham, 2000; Ribbens McCarthy, 2006), raising questions about its nature (Rolls, 2007a).

This deterministic view has been challenged by Pollock (1983) who suggests that the socialisation of children is always culturally constructed through the collective actions of adults and children (Rolls, 2007a). In contrast to those viewing growth and development as passive and unilateral, this sociologically embedded, constructivist model of development sees the child as an active, creative agent in their development rather than a passive consumer of adult culture. Corsaro (1997, p. 30) argues that children 'contribute to the *reproduction* of childhood and society through their negotiations with adults and their creative *production* of peer cultures with other children' (emphasis added).

Until recently, the opinions of children have not been heard (Alldred, 1998), except through adult accounts (Brannen & O'Brien, 1996), they have possessed few rights (Foley, 2001) and have been subject to the role of adults in shaping policies that affect them (Rolls, 2007a). This is evident in recent policies of enhanced recognition of children's rights and agency (United Nations, 1989) and the appointment of both a Minister for Children and Young People in Scotland and England and children's commissioners across the UK. Nevertheless, public policy and practice is exerting an increasing degree of institutional control, surveillance, and regulation in children's lives (Mayall, 1999; Prout, 2000), as well as consigning children in many areas of the UK to poverty and deprivation (Wickham, Anwar, Barr, Law, & Taylor-Robinson, 2016; Churchill, 2018), as a result of which the material conditions and experiences of children, including that of bereavement, are not equally distributed (Ribbens McCarthy, 2006). In challenging this tendency to dismiss children's insights, knowledge, and contributions to the culture, Corsaro (1997) draws on Qvortrup's (1994) idea of childhood as a 'structural form' to argue that childhood, as a social form in society, is also subject to and influenced by the wider social changes.

Theories of childhood bereavement

The 20th century has been characterised by the development of, often contested, definitions of bereavement, grief and mourning, as well as of a widening range of bereavement discourses. The terms 'bereavement', 'grief', and 'mourning' are all associated with the phenomena of experience that follows the death of a significant person, but the different literatures use these in various and sometimes contradictory ways (Rolls, 2007a). Katz's (2001, p. 4) comment that each carry 'different implications for what might be termed as "adjustment"' still holds true 18 years onwards. Furthermore, across the century, bereavement discourses (the theoretical perspectives and models) have developed from the earlier universalist/modernist theories to more recent cultural/identity models. This shift can be seen in the 'journey' from the early psychoanalytic approaches postulated by Freud (1917) and Bowlby (1980/1998) to the newer psychosocial understandings of Parkes (1975/2010) and Stroebe and Schut (1999) and, latterly, to the more recent socio-cultural perspectives of Walter (1996), Neimeyer (2001), and Klass, Silverman, and Nickman (1996).

What is being expressed, within the competing definitions and different uses of terminology, is the complexity and tensions that lie within, and between, different disciplines in their view of the universality of a human experience versus the role of social construction within it; that is, in the relationship between the individual and their internal world of affect, and the individual and their external social world. This, in turn, raises the question of 'authority', that is, what contribution each perspective brings to the understanding of bereavement, grief and mourning, and whether some can be privileged over others. This is not the place to fully explore bereavement theories and models (see Valentine (2006) and more recently, Pearce (2019) for an interesting critique), but what is important here is that these they are derived from, and directed towards, the experience of *adults* to provide varying (mostly but not always theoretically derived) explanations for the impact of bereavement and, thus, an account of what supportive activities can ameliorate these. They do not specifically provide an account for the bereavement of children as they develop and mature, especially one derived from *their* experience and which privileges *their* voice (Rolls & Payne, 2007). Exceptions to this include Worden's (1996) 'task' theory which developed from the Harvard children's study, and Bowlby's (1998/2010) theory of attachment and the consequence of loss, derived from his observation of children, although not originally developed specifically in relation to a loss through death. Although based on the retrospective memory of adults who experienced this loss in childhood, Holland's (2001) work is an attempt to understand the experience of school-age children who were bereaved through the death of a parent (Rolls, 2007a) and, more recently, Chowns (2013) pre-bereavement research has provided a vehicle for adolescents to speak for themselves.

In addition to an uncertainty about the nature of children's bereavement, there are cultural changes in the way in which grief is being expressed. In an increasingly secular society in which religiously-based community rituals have diminished, the deconstruction of shared rituals can result in the deterioration of *meaning* (Romonoff & Terenzio, 1998) – a dimension considered important in bereavement (Neimeyer, Baldwin, & Gillies, 2006). Without a set of shared practices and rituals that inform the 'appropriate' action of adults, the situation of children has become increasingly precarious (Rolls, 2009).

So what is understood about childhood bereavement especially as, despite earlier questions concerning the long-term impact that bereavement may have (Harrington, 1996; Harrington & Harrison, 1999), this event is seen as an important determinant for adult psychiatric health (Lytje & Dyregrov, 2019)? While not providing such a 'neat' explanation as some adult theories, two perspectives provide an account of children's experience (and for an extensive review of what is known about childhood bereavement, see Penny & Stubbs, 2015). The first perspective relates to the potential consequences of childhood bereavement and the second to mediating factors of that experience.

Potential consequences

Lytje and Dyregrov (2019) argue that most children will manage to do well and find a level of functioning following the loss of a parent, but that there are many, potentially negative, consequences relating to psychological, physical, and social parameters – in some cases leading to persistent and lifelong effects. Furthermore, they maintain that there are challenges in isolating the family's pre-death socio-economic circumstances that are important in determining possible associated risks. Bereaved children have been described as the 'forgotten mourner' (Hindmarch, 1995), feeling isolated within the privatised nuclear family (Rolls, 2008), as well as from their peers and within the school setting where they may be marked out as 'other' and targets for bullying (Cross, 2002; Rowling, 2003; Rolls & Payne, 2007). Other studies implicate childhood bereavement in (among others) serious illness (Worden, 1996; Fauth, Thompson, & Penny, 2009); higher mortality risk (Li et al., 2014); increased risk of negative health behaviours (Sweeting, West, & Richards, 1998; Parsons, 2011); emotional and mental health challenges including depression (Worden, 1996; Fauth et al., 2009; Parsons, 2011) and risk of suicide (Wilcox et al., 2010; Jakobsen & Christiansen, 2011). The loss of a sibling presents a different set of challenges for a bereaved child. They may need to negotiate feelings of guilt and self-reproach as well as the ambivalent feelings often found in sibling relationships (Dyregrov, 1991) and, where there has been a death as a result of a life-limiting illness, the well siblings will have already been living in 'houses of chronic sorrow' (Bertman, 1991, p. 320; citing Bluebond-Langner, 1989). Like children experiencing parental loss, there may be long-term implications for surviving siblings, including difficult behaviours (Davies, 1991) and a higher risk of psychiatric disorder in childhood (Rutter, 1966) and in later life (Black, 1996).

Childhood bereavement can thus be seen as a potentially severe developmental threat, including to their self-esteem and resilience, arising from the disruption of attachment bonds and the caregivers' availability in shaping children's confidence and feelings of security (Kobak & Madsen, 2008), and for which their responsive coping strategies in the form of risk-taking behaviours – for example, drug use, self-harm; avoidant or aggressive behaviour – may in turn become a cause for concern.

Mediating factors

A number of interactive factors are understood to mediate the experience and impact of bereavement including:

- the child's characteristics, including gender, age, level of cognitive and emotional development (Christ, 2000; Dowdney, 2000) that influence the impact of a child's reaction to bereavement, especially as, unlike adults, they do not have strategies to minimise or avoid the psychological pain of grief (Archer, 1999), and may experience a desperate struggle in trying to understand and cope with overwhelming and unexpected feelings (Ribbens McCarthy & Jessop, 2005);
- the circumstances around the death, including how the person died (Dietz et al., 2013), whether it occurred suddenly or was anticipated, how and what children are told, and if and how involved they are involved in the funeral (Harrison & Harrington, 2001);
- their relationship to the person who has died, including, in the case of their parent, the loss of 'their partners in negotiating the essential developmental tasks that will take them to adulthood' (Worden, 1996, p. 9);
- the consequences as a result of the loss, including the capacity of who remains (Christ, 2000) to provide for the physical and emotional needs of children when they themselves are under a 'considerable psychological strain' (Parkes, 1986, p. 163) struggling with their own bereavement and the profound disruption in their social

circumstance; what life is like afterwards (Worden, 1996) including the potentially radical shift in the familiar design of family life (Rolls & Payne, 2007), and their subsequent relationships with peers and school (Ribbens McCarthy & Jessop, 2005; Dyregrov, 2008).

The development of childhood bereavement services within the UK

In the UK, the development of childhood bereavement services into individual organisations that provide some level and form of intervention for children and their families gained momentum in the early 1990s, although concern among a range of professionals for children's welfare following bereavement precedes this. The number of UK childhood bereavement services was then, and still remains, difficult to assess as this data is not collected centrally. Some existing services were not known about during recruitment to the 2001 survey, more services have since been developed, while some have closed often due to a lack of funding (Rolls & Payne, 2003). This growth of services was advanced through three inter-related domains of activity that were increasingly having (and continue to have) a dynamic influence on each other – the practices derived from professional knowledge and the experience of working with bereaved children and their families; research data concerning bereaved children that informed, influenced and supported this; and the sharing of knowledge and experience through training and networking.

Practices derived from experience and professional knowledge

With a few exceptions, the emergence of services arose from the ongoing bereavement support work where individual practitioners responded to parents' requests for help supporting their child(ren). This occurred largely, although not exclusively, in palliative care settings where death was anticipated and where there was very little in the way of supportive literature or responses that specifically addressed the needs of these children (Monroe, 2013).

During the early 1990s, practitioners' activities were developing into more formalised organisational structures, and examples of this phenomena include *Winston's Wish*, founded in 1992 by Julie Stokes, a clinical psychologist working in palliative care; what is now *Child Bereavement UK (CBUK)*, founded by Jenni Thomas, a nursery nurse on a special care baby unit, and launched and established with Julie Samuel as founder patron in 1994; and *Jeremiah's Journey*, founded in 1996 by four professionals Dr Jacqui Stedmon, a clinical psychologist; Dr Sheila Cassidy, a medical doctor; Diana Maynard, a social worker; and Ann Tucker, a clinical nurse specialist. Subsequently, services have also been set up by bereaved parents as a charitable trust in memory of their deceased child (for example, Gail and Harry Moore founding *the Laura Centre* in 1991); and by charities extending their provision to include bereaved children (for example, *Penhaligan's Friends* founded in 1995 through the work of a bereavement forum representing a wide number of organisations including CRUSE, CLIC, Compassionate Friends, SANDS, SIDS, Child and Family Services, Macmillan Service, Hospital Chaplaincy, Hospice South West and social services). At the same time, both adult and children's hospices were providing support for bereaved children originally linked to an in-patient relative but then, in many cases, extending to the wider community (for example, the *Candle Project* at (the adult) St Christopher's Hospice launched in 1998 and the bereavement service at Derian House Children's Hospice founded in 1999). This growth in services was mirrored across the UK. By 1998, Barnardo's Child Bereavement Service in Belfast, Sandy Bear Bereavement Service in Pembrokeshire and Yorkhill Children's Hospital and Rachel House Children's Hospice were also providing childhood bereavement support.

By 2001, there were 127 known services – either 'freestanding' organisations or offered within the range of work of a 'host' organisation (such as a hospice or a counselling service) with a supporting organisational structure whose purpose was to offer some form of intervention for childhood bereavement. Of these services, 57% (n=52) had been offering a service prior to 1998, while a further 30% (27) had begun during the period 1998 to 2000 (Rolls & Payne, 2003). In addition, in a response to an increasingly expressed need, literature for bereaved children began to emerge. These were initially devised by practitioners and, in many cases, then formalised into published pre- and post-bereavement workbooks (for example, Ann Couldrick's (1991) *When your Mum or Dad has cancer* previously provided in leaflet form, and Marge Heegaard's (1991) activity book *When someone very special dies: Children can learn to cope with grief* (Monroe, 2013).

What this brief outline of the genesis of some of the early formalised services demonstrates is the extent to which, initially at least, the underpinning knowledge base of the professions within and between services varied, depending, to an extent, on the discipline within which the service was founded and is now located (educational, psychotherapeutic, psycho-educational, social work, etc). Furthermore, supportive interventions for bereaved children are located within a diverse and complex tapestry of service provision, in terms of location, type of services, service organisation, funding arrangements and the type and models of intervention they offer (Rolls & Payne, 2003). They are also offered to children and their families in different ways across the sector: individually or in groups, with a child only or with/through their families, and Figure 1 below shows this range of activity.

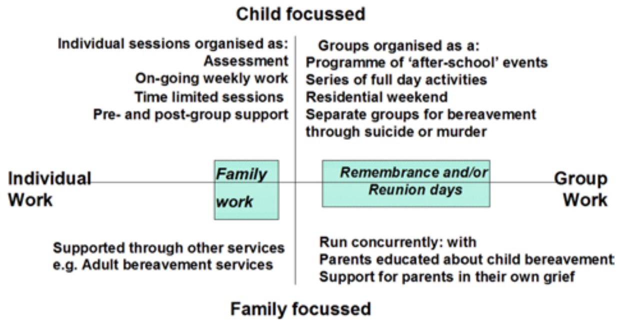

Figure 1: Range of direct service provision (Rolls & Payne, 2004)

Alongside some form of face-to-face engagement, support is also enabled through a repertoire of the bereavement-specific experiential endeavours that practitioners have developed, including resources, workbooks, games such as Barnados' *All about Me*, and activities such as puppetry, making pictures, collages, memory boxes and salt sculptures. These contribute to helping children name feelings, think about the person who has died and about what has happened, and how they can help and support themselves in the future (Rolls & Payne, 2004). For some, this has resulted in post-traumatic growth (Brewer & Sparkes, 2011a). Increasingly, services are offering psycho-education and support, not only in person but also via website information, the provision of a platform for a web-based peer support, and through email or telephone helplines. Although forming a part of the work from the start (Monroe, 2013), there has also been an expansion in specialist support to children bereaved through particular causes of death such as murder or suicide or through other traumatic events. In addition, attention is increasingly being given to children's pre-bereavement needs – preparing the way where a death is anticipated (Penny, 2018).

While overall services offer a comprehensive range of provision, they recognise that not all children and their parents require specialist therapeutic interventions. Rather, depending on their circumstances, including the presence of a supportive family and social circle as well as an understanding school environment, different levels of provision need to be available. These are illustrated in Figure 2.

Research data

The diverse approaches that services offer have largely arisen from within the professional knowledge base of the founding practitioner(s) and are, thus, influenced by their professional 'philosophical' orientation towards children. Coupled with practitioners' broadening understanding derived from their work with families where a child had been bereaved, approaches and strategies were also influenced by an increase, during the 1980s and 1990s, in research on childhood bereavement (Black, 1983, 1991, 1996; Black & Urbanowicz, 1987; Pennells & Smith, 1995; and Worden (1996) followed by – among others – Christ, 2000; Dyregrov, Gupta, Gjestad, & Mukanoheli, 2000). As a result of the synergy of practice, experience, and research, practitioners were '*beginning to get the texture of evidence as well as practice*' (Monroe, 2013). Worden (1996) in particular was influential in articulating children's need for adequate information; having their fears and anxieties addressed; being offered reassurance about their place in events; being helped with their validated feelings; and having opportunities to remember. This synthesis of practice and evidence also began to appear in practitioner research that articulated different modes of support (see for example, Dent & Stewart, 2004). Others have since extended their research interest into the type of childhood bereavement – for example work in relation to bereavement through illness such as cancer

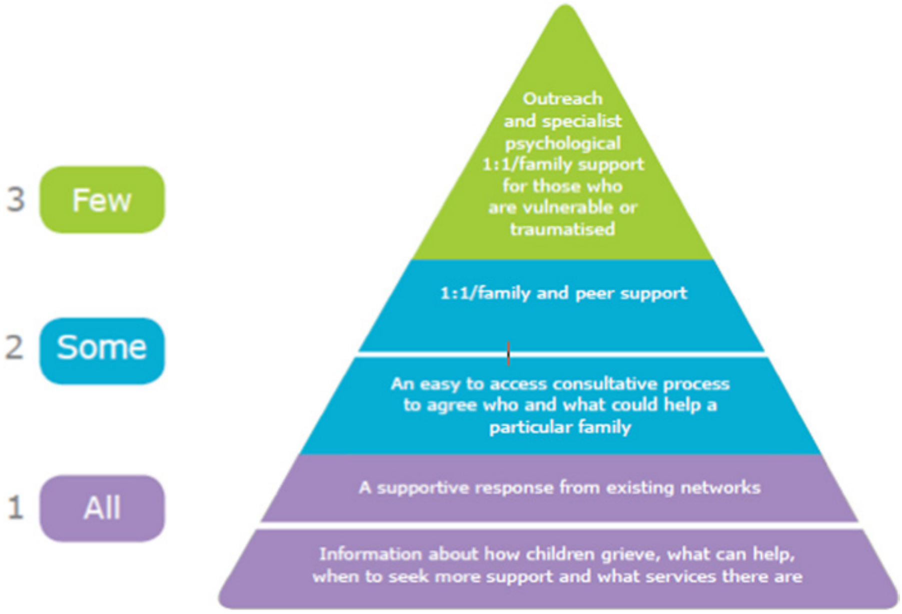

Figure 2: What good provision for bereaved children and young people and their parents and carers looks like (Childhood Bereavement Network, undated).

(Couldrick, 1992; Grinyer, 2012), and to the settings in which children's bereavement may be being experienced or expressed; for example, Yule and Gold (1993) and later Rowling and Holland's (2000), and Rowling's (2003) research, has influenced the support of children in schools.

Alongside these developments, practitioners were also beginning to write about the needs of bereaved children and approaches to support. These early writings described: the needs of bereaved children (eg Monroe & Kraus, 1996); the practical issues involved in developing services (eg Stokes, Pennington, Monroe, Papadatou, & Relf, 1999; Melvin & Lukeman, 2000; Worswick, 2000); types of interventions that services use (eg Fleming & Balmer, 1991; Thompson, 1995; Stokes & Crossley, 1996; Potts, Farrell, & O'Toole, 1999; Paton, 2004); and the development of assessment tools for childhood bereavement services (eg Birenbaum, 2000); as well as the results of evaluations of a particular service (eg Williams, Chaloner, Bean, & Tyler, 1998; Phillips & Burt, 1999). There had also been a review of services available in the UK for children who had been bereaved (eg Blanche & Smith, 2000) as well as a more recent review of the impact and educational outcomes of childhood bereavement services (eg Ackerman & Statham, 2014). Despite this extensive and extending literature, the work of Rolls and Payne (2003, 2004, 2007, 2008; and Rolls, 2009, 2007a) remains the only ethnographic study that describes the range, aspects, and complexity of the work of UK childhood bereavement services *as a whole*.

Training and networking

In addition to developing their understanding and writing about the needs of bereaved children, practitioners became engaged in training and cultivated networks to support current and emerging services.

As their experience and work developed, many practitioners sought additional training and development, for example through supervision with Dora Black and Colin Murray Parkes or at the Institute of Family Therapy (Oliviere, 2013), or learning from other experienced practitioners. For example, Winston's Wish was developed after Julie Stokes used her Winston Churchill Fellowship to visit childhood bereavement services in the USA (1992). Practitioners also began to provide training opportunities for others. In the 1990s, Denise Brady and Barbara Monroe organised a series of trainings funded by Help the Hospices that was attended by diverse groups (Monroe, 2013). Winston's Wish, an early pioneer, ran training courses outlining a model of support (Stokes, 2004) that many services adopted in their early days and then adapted to meet the needs of their own communities. In addition, as local services developed, they began to offer specific training for their 'secondary users' – other services such as the police and family liaison officers, the emergency services, schools and the media (Rolls & Payne, 2003). More formal education and training also began to develop. The Open University started its course on death and dying in 1990 (Draper, personal communication), while in 2004, St Christopher's Hospice created an undergraduate diploma and a postgraduate certificate in childhood bereavement, validated by Middlesex University, run in partnership with Hospice UK (Monroe, 2013; Oliviere, 2013). These initiatives have been accompanied by significant resource development.

Two significant professional networks also emerged to support the work of childhood bereavement services. The Bereavement Research Forum (BRF) was founded in the mid-1990s by Sheila Payne, Marilyn Relf and Linda Machin to support emerging UK-based bereavement researchers. As it developed, it provided a wider forum to support and encourage both producers (researchers) and users of research (both academics and practitioners) and to debate current and future research not only in adult bereavement but – importantly – in the emerging interest in children's bereavement. The BRF is now subsumed under the National Bereavement Alliance[2] as a special interest group concerned with encouraging bereavement research into practice.

The second and most significant network – the Childhood Bereavement Network (CBN)[3] – began as the Childhood Bereavement Project (CBP), set up in 1998 under the aegis of the National Association of Bereavement Services (a national umbrella membership organisation) following an approach by Marie Curie and St Christopher's Hospice, who were keen to co-ordinate and develop an integrated approach to childhood bereavement service provision across UK. This original idea was to include a registration scheme and support for education, research and training (Monroe, 2013). Following some difficulties with funding and location, the CBP transferred to be hosted by the National Children's Bureau in 2000 changing its name the following year to the Childhood Bereavement Network. This move ensured that the focus of childhood bereavement was now located within the mainstream of child welfare provision. Sarah Willis, the original development officer for the CBP, worked closely alongside Jonathan Hartley who led the project to develop nationally agreed bereavement care service standards.[4] The current

---

[2] National Bereavement Alliance: An alliance of individuals and organisations whose purpose is to support those who work with bereaved people. See https://nationalbereavementalliance.org.uk

[3] The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK. They underpin their members' work with essential support and representation: bringing them together across localities, disciplines and sectors to improve bereavement care for children. See www.childhoodbereavementnetwork.org.uk/about.aspx

[4] The Bereavement Care Service Standards, further developed in 2013 to reflect the evolution of bereavement care in the statutory sector, are available at: www.cruse.org.uk/sites/default/files/default_images/pdf/Documents-and-fact-sheets/Bereavement_Care_Service_Standards.pdf

CBN – as a membership organisation with representation from organisations such as childhood bereavement services, hospices, schools, charities and training groups, as well as individuals such as social workers, faith leaders, funeral directors, teachers, counsellors, and researchers – reflects the diversity and extent of professionals engaged in providing support to bereaved children and their families. Over its life date, the CBN has produced resources and developed supportive material for both families and services, including to *A guide to developing good practice in childhood bereavement services*. In addition, the CBN Childhood Bereavement Service Outcomes Framework[5] assists the assessment of the environment and processes that services need to provide to enable them to achieve the outcomes of their service use (for example, 'Has age-appropriate information about the death: a narrative that makes sense'; 'Levels of distress don't interfere with functioning at home, school and with friends') – that in turn contribute to outcomes over time (for example, 'Has confidence about the future'; 'Adjusting well to a changed life (resilience)'.

Current challenges

The sector faces many challenges and opportunities, including those presented by digital transformations; changes in the wider mental health field; how services develop their patterns of delivery and understanding of need; as well as from changes in the wider social and political landscape. Amongst these, three inter-related areas continue to impact on services' capacity to develop and maintain provision for bereaved children: social policy, funding, and research.

Social policy

Policy is closely intertwined in how death is experienced (Foster, Woodthorpe, & Walker, 2019). As a result, it has a bearing on the bereavement experience of children, including through those policies that impact favourably or unfavourably on their caregivers. For example, the consequences of policies associated with changes in bereavement benefits have an identifiable impact on claimants' children (Corden, Sainsbury, & Sloper, 2004; Simpson, 2018). However, Foster et al. (2019, p. 12) argue that, 'while policies associated with children and childcare, employment and pensions have received considerable attention over recent years, those associated with death require a greater role on the policy agenda'. This is of particular importance where the resources of a community – both social and economic – are limited. A decade of austerity policies in the UK has had a disproportionate affect on those with low income and on children, placing these families under greater stress as a result of bereavement. Furthermore, the community itself may be less likely to have the capacity to lobby for and/or support a bereavement service for children. Efforts to support communities – through 'bottom up' capacity – building in areas of deprivation – have been made, for example by CBUK, while local lobbying and advocacy has resulted in the commissioning of a childhood bereavement service by Leeds City Council. At national level, CBN has been called before the House of Commons Work and Pensions Select Committee to give evidence on the impact of the new Bereavement Support Payment and Universal Credit on grieving children and their parents, and the recommendations to government are expected later in 2019.

Nevertheless, a key question concerns the extent to which children's bereavement is considered at national policy level. Recent policies have the potential to impact on bereaved children and their families. For example, the recent *End of life care strategy* (Department of Health, 2008) recognises the role of children in the provision of care of the dying and of the potential need for support following the death, while the *NHS Long term plan* (2019) also includes a commitment to put in place suicide bereavement support for families in every area of the country. Placing childhood bereavement in the wider context of mental health, *Future in mind* (Department of Health, 2015) is concerned with the prevention/promotion of resilience, prevention and early intervention, and *Character and resilience: A call for evidence* (Department for Education, 2019) is also an example of a commitment to improve children's mental health particularly through the development of resilience. The Green Paper *Transforming children and young people's mental health provision: a Green Paper* (DOH/DfE, 2017) proposed to build on emerging practices resulting from the schools link pilots and establish new mental health support teams, supervised by NHS children and young people's mental health staff and linked to groups of schools and colleges.

However, some argue that, 'a lack of clarity on governmental and school polices on mental health and bereavement has led to both confusion and disagreement on the forms of support schools should offer and the extent of that support. This has led to a somewhat random approach to the forms of support currently provided to bereaved children in British schools' (McLaughlin, Lytje, & Holliday, 2019, pp. 14–5), and it is interesting to note that *Transforming children and young people's mental health provision: a Green Paper* (DOH/DfE, 2017) makes no mention of the work of childhood bereavement services with schools. Furthermore, as these few examples highlight, attention to children's bereavement is fragmented across different government policies and, as we have seen, may not directly be addressed but is subsumed (and possibly

---

[5] For more information about the Childhood Bereavement Service Outcomes Framework and the Child Bereavement Service Questionnaires, see www.childhoodbereavementnetwork.org.uk/running-a-service/evaluating-a-service.aspx

assumed) under the broader context of children's mental health. To ameliorate these difficulties, Foster et al. (2019) argue for a new policy framework for death that would take a life course perspective and that a coherent policy response to death should be further characterised by a joined-up approach.

Funding

Funding is closely linked to policy. The National Children's Bureau (2019) has identified that funding available for children's services has fallen by a third per child in England since 2010. Thus, like many health and social care services within both the statutory and voluntary sectors, the 'austerity' agenda has resulted in cuts to, or loss of, income streams to childhood bereavement services, and funding their activities remains one of the ongoing challenges with which they continue to struggle. This can have a detrimental impact on the core business of some of the services, as well as on their ability of the service to develop and meet increasing demand from primary and secondary service users (Rolls & Payne, 2004).

While the voluntary and community sector is key to helping address mental health challenges and there have been political pledges to increase mental health related funding, there is a long way to go before mental health achieves 'parity of esteem' with physical health (Weakes, 2015). Furthermore, one of the 'knock-on' effects of funding restrictions on the statutory sector is the increasing demand being placed on the voluntary sector to fill the gap (New Statesman, 2015). As has been argued elsewhere in broader parenting support programmes, Moran and Ghate (2005) suggest that targeted, intensive services have been shown to benefit high-risk families, but they argue that there is also a place for early intervention with families at the lower end of the risk spectrum. Given the impact on service provision by these constraints of funding, services are unable to make provision available to all those who ask for it (Rolls & Payne, 2007) or indeed, to those who need it. In restricting access to those who seek support to more specialist and/or targeted provision, there are questions about referral criteria and how services turn away families approaching them with expressed need (Bradshaw, 1972).

Research

Linked to this, there is an urgent need for more research. Statistics derived from baseline data together with research that provides evidence of efficacy and outcome enhances services' chances of securing funding, and practitioners have been keen to evaluate their work – indeed are subject to an evaluation burden arising from the extensive and diverse requirements of, for example, funders and commissioners (Rolls, 2007b). However, in the absence of a validated pre-post measure for bereaved children, services had relied on other instruments alongside 'satisfaction' questionnaires providing 'soft' qualitative data. Following a research-based recommendation to develop a common-core 'clinical' outcome evaluation measure (Rolls, 2007b), the CBN – with bereaved children, young people and their families, service providers, funders and commissioners as well as researchers in the field – has developed a suite of outcome measures specifically for childhood bereavement services.[5] Collection of this data over time and across services will mean individual services can monitor the impact of their work and judgements can be made about the wider impact of the sector as a whole. With the publication of a recent rapid evidence assessment concerning the provision and effectiveness of bereavement support in the UK that excluded papers on children's bereavement (Hewison, Zafar, & Efstathiou, 2019), it is increasingly important for services to generate and publish evidence of their impact.

In addition, much still remains uncertain. Penny and Rice (2012) have identified a number of research priorities, including the need for: more longitudinal data for a cohort of children and young people to track their experience of bereavement and the impact this has on their life course over the short, medium and long term; evidence about complicated or prolonged grief in children and young people; and the effectiveness of different approaches. In addition, there needs to be investigations from a sociological perspective, as well as research with children, young people and families who have not accessed services.

The impact of UK childhood bereavement services

What is clear from this brief review of the development of services is the richness of the UK childhood bereavement sector – in terms of the extensive knowledge and experience, practices, research and training – that has developed in the short time since the late 1980s. However, assessing their impact is not an easy task, in part because the impact of bereavement on children is itself uncertain. Nevertheless, it is helpful to consider the two ways in which their influence on individuals and on the wider culture can be recognised.

The influence on the wellbeing of individual children

Individual services have had a beneficial influence on the experience of bereaved children and their families who have made some level of use of their service (Rolls & Payne, 2007; Stokes, 2009; Brewer & Sparkes, 2011b). While individual services articulate a specific purpose, their overall implicitly shared significance is that, through their endeavours, they provide a secure place to enable bereaved children to create memory and story through an exploration of their experience of bereavement, enabling them to access their unspoken and unconscious feelings, and to make sense of what had happened and how they feel. Their interventions help 'normalise' children's experience; assist them in managing these feelings; contribute to improving communication between family members; reduce feelings of isolation; and, crucially, hold the possibility of hope for their future *(*Rolls & Payne, 2004).

In enhancing children's capacity through these experiences, services develop children's 'transferable' skills that help them meet other challenges in life (Brewer & Sparkes, 2011a). Importantly, services act as a parenting support service (Moran & Ghate, 2005) in which parents are supported not just on their own account, but also in parenting their bereaved child (Rolls & Payne, 2007). These endeavours – generated intuitively alongside earlier research including Worden's (1996) study – are recognised as evidence-based practices that contribute to addressing the empirically-supported, malleable factors that have been shown to contribute to or protect children from mental health problems following the death of a parent (Haine, Ayers, Sandler, & Wolchik, 2008).

The wider influence of UK childhood bereavement services

Services have had a significant influence on wider culture. Drawing on Qvortrup's (1994) notion introduced earlier, childhood bereavement services are a structural form of health and social care provision for children that has arisen in the specific cultural and historical context of the late 20th century developed world, and it is in this context that they have influenced the social construction of bereaved children and on cultural discourses concerning them. Some argue that children are still subject to different forms of abuse and 'separated into the *social institution of childhood*, have found adults deaf to their unhappiness, confusion and sense of loss' (Foley, 2001, p. 2, emphasis added). In taking bereaved children seriously, practitioners have been instrumental in transforming not only individual lives but also the cultural discourse concerning both bereavement and children – in particular, how to enable children to accommodate loss into their life narrative. This influence can be seen in different ways, including in the extent to which issues concerning bereaved children have, over time, entered mainstream media and public – as well as other professionals' – discourse. This discourse is one of normalising children's experience of bereavement, but it also adopts a preventative model by offering children a purposeful, containing space in which to 'think' about, and learn from their experience, and gain mastery (Rolls, 2007; Brewer & Sparkes, 2011a).

However, the increasing recognition by services that children's bereavement is more precarious in areas of deprivation, where access to supportive resources (and not just for bereavement) can be lacking, reflects the view that children's bereavement experience is shaped by a wide range of social, economic, political and organisational forces, many of which are outside the control of families and especially of the children within them.

As a result, several services are adopting a more community development model. Through training and strategic activities that influence policies and provision at local level, childhood bereavement services have made an important contribution to building the capacity of communities to support bereaved children, whilst collectively, through their membership of CBN, services have been instrumental in advocacy, lobbying and campaigning at national level on issues of concern to bereaved children and their families – actions that represent an attempt to redress the 'structural indifference' (Fattore, Mason, & Watson, 2016) to which children in general and bereaved children in particular are subjected. This form of collective activity on behalf of bereaved children has proved to be an inspiration internationally. The UK plays an important role in the Family Bereavement Network Europe, and a commissioned scoping study (McLoughlin, 2012) led to the customised development of the Irish Childhood Bereavement Network (ICBN).[6] This synergy between countries encourages further developments. Figure 3 shows how ICBN have elaborated the framework outlined in Figure 2 to include the needs that bereaved children and their families have at each level of service/support together with the competencies required to meet these.

Conclusion

What is clear is that through their work, childhood bereavement services provide an 'ecological niche' – an 'event' which is 'favourable or unfavourable for the development of individuals with particular characteristics' (Bronfenbrenner, 1992, p. 194), by acting on the ecological systems of the bereaved child (Bronfenbrenner, 1992). Individually and as a structural form, through their engagement in a variety of practices which impact directly and indirectly on these systems, services are continuing to encourage and enable these environments to take the needs of bereaved children into account. They are increasingly playing an important role in influencing bereaved family narratives and children's memorialising practices (Rolls, 2009) as well as defining cultural assumptions and beliefs about children and their experience of bereavement. In filling the vacuum arising from cultural anxiety about children and about death (Mellor, 1993), they are taking children seriously;

---

[6] For more information about the Irish Childhood Bereavement Network see: www.childhoodbereavement.ie

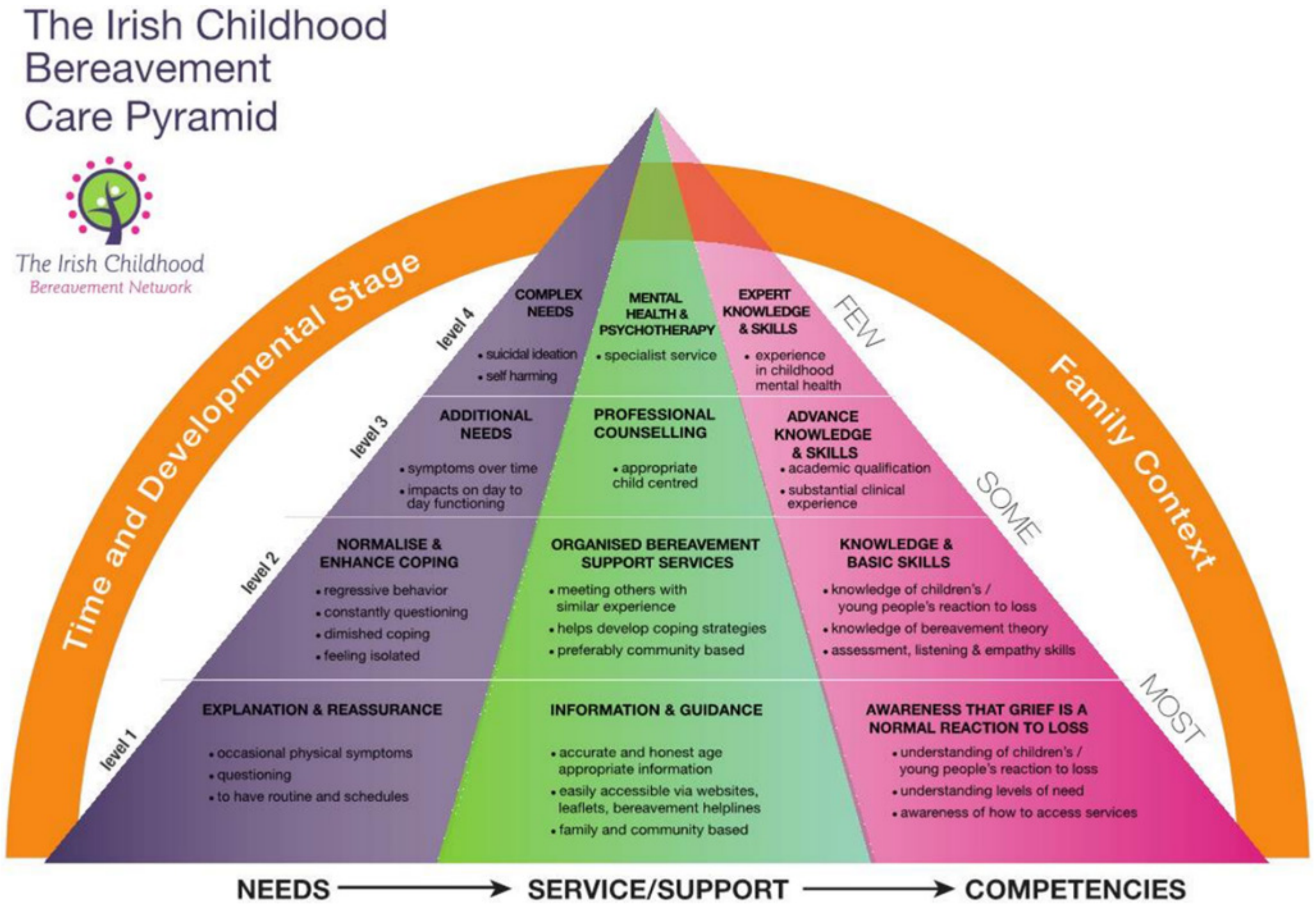

Figure 3: The Irish Childhood Bereavement Care Pyramid (ICBN, 2014)

acknowledging their active agency; conferring dignity and importance to the experience of their own affective life, including their grief; bringing children's experience of bereavement out of the private into the public domain; and encouraging a congruence between the state, and display, of feelings that could be considered more authentic than the culturally determined dissonance that has surrounded bereavement, including childhood bereavement. They are increasingly advocating and campaigning on behalf of children who have been bereaved at local and national levels through the media and in government, as well as providing a vehicle through which the voices and experiences of children who have been bereaved can be heard in their own right. Thus, it can be argued, through their contribution to transforming cultural beliefs and attitudes towards children who have been bereaved, UK childhood bereavement services are not just passive reproducers of culture, rather – and this is perhaps their greatest impact – they have increasingly become *producers* of cultural attitudes and norms concerning childhood bereavement (Rolls, 2007a). ■

Acknowledgement

I am very grateful to the three reviewers for their encouragement and thoughtful comments on an earlier draft of this paper. These were much appreciated.

ORCID

Liz Rolls http://orcid.org/0000-0001-9225-5497

Ackerman, R., & Statham, J. (2014). *Bereavement in childhood: The impact on psychological and educational outcomes and the effectiveness of support services*. Working Paper No. 25. London: Thomas Coram Research Unit, Institute of Education.

Alldred, P. (1998). Ethnography and discourse analysis: Dilemmas in representing the voices of children. In J. Ribbens, & R. Edwards (Eds.), *Feminist dilemmas in qualitative research: Public knowledge and private lives* (pp. 147–170). London: Sage.

Archer, J. (1999). *The nature of grief: The evolution and psychology of the actions to loss*. London: Routledge.

Ariés, P. (1962). *Centuries of childhood*. New York: Vintage.

Bertman, S. I. (1991). Children and death: Insights, hindsights and illuminations. In D. Papadatou, & C. Papadatou (Eds.), *Children and Death* (pp. 311–329). New York: Hemisphere.

Birenbaum, L. K. (2000). Assessing children's and teenagers' bereavement when a sibling dies from cancer: A secondary analysis. *Child: Care, Health and Development*, *26*(5), 381–400.

Black, D. (1983). Bereaved children-family intervention: A research report. *Bereavement Care*, *2*(2), 4–11.

Black, D., & Urbanowicz, M. A. (1987). Family intervention with bereaved children. *Journal of Child Psychology and Psychiatry*, *28*(3), 467–476.

Black, D. (1991). Family intervention with families bereaved or about to be bereaved. In D. Papadatou, & C. Papadatou (Eds.), *Children and death* (pp. 135–143). New York: Hemisphere.

Black, D. (1996). Childhood bereavement: Death and long term sequelae can be lessened by early intervention. *British Medical Journal*, *312*, 1496.

Blanche, M., & Smith, S. (2000). Bereaved children's support groups: Where are we now? *European Journal of Palliative Care*, *7*(4), 142–144.

Bluebond-Langner, M. (1989). Worlds of dying children and their well siblings. *Death Studies*, *13*, 1–16.

Bowlby, J. (1980/1998). *Attachment and loss. Vol. 3: Loss, sadness and depression*. London: Pimlico. (First published in 1980 by London: Hogarth Press).

Bradshaw, J. (1972). A taxonomy of social need. In G. McLachlan (Ed.), *Problems and progress in medical care*. Essays on current research, 7th series (pp. 71–82). London: Oxford University Press.

Brannen, J., & O'Brien, M. (1996). Introduction. In J. Brannen, & M. O'Brien (Eds.), *Children in families: Research and policy* (pp. 1–12). London: Falmer Press.

Brewer, J. D., & Sparkes, A. C. (2011a). Parentally bereaved children and posttraumatic growth: Insights from an ethnographic study of a UK childhood bereavement service. *Mortality*, *16*(3), 204–222.

Brewer, J. D., & Sparkes, A. C. (2011b). Young people living with parental bereavement: Insights from an ethnographic study of a UK childhood bereavement service. *Social Science and Medicine*, *72*(2), 283–290.

Bronfenbrenner, U. (1992). Ecological systems theory. In R. Vasta (Ed.), *Six theories of child development* (pp. 187–249). London: Jessica Kingsley.

Buckingham, D. (2000). *After the death of childhood: Growing up in the age of electronic media*. Cambridge: Polity.

Childhood Bereavement Network (undated). *Grief matters for children*. Retrieved from www.childhoodbereavementnetwork.org.uk/media/57656/Grief-Matters-for-Children-2017.pdf [accessed 21 July 2019].

Chowns, G. (2013). 'Until it ends, you never know…': Attending to the voice of adolescents who are facing the likely death of a parent. *Bereavement Care*, *32*(1), 23–30.

Christ, G. (2000). *Healing children's grief: Surviving a parents death through cancer*. Oxford: Oxford University Press.

Churchill, H. (2018). *No 39: Austerity adversely targets children in need*. Social Policy Association. 50th Anniversary Blog Series. Retrieved from www.social-policy.org.uk/50-for-50/austerity-children/ [accessed 14 March 2019].

Corden, A., Sainsbury, R., & Sloper, P. (2004). Money matters and bereavement support. *Bereavement Care*, *23*(2), 19–21.

Corsaro, W. A. (1997). *The sociology of childhood*. London: Pine Forge Press.

Couldrick, A. (1991). *When your Mum or Dad has cancer*. Oxford: Sobell Publications.

Couldrick, A. (1992). Optimizing bereavement outcome: Reading the road ahead. *Social Science and Medicine*, *35*(12), 1521–1523.

Cross, S. (2002). *'I can't stop feeling sad': Calls to ChildLine about bereavement*. London: ChildLine.

Davies, B. (1991). Responses of children to the death of a sibling. In D. Papadatou, & C. Papadatou (Eds.), *Children and death* (pp. 125–133). New York: Hemisphere.

Dent, A., & Stewart, A. (2004). *Sudden death in childhood: Support for the bereaved family*. London: Butterworth Heinemann.

Department for Education (2019). *Character and resilience: A call for evidence*. Retrieved from https://consult.education.gov.uk/character-citizenship-cadets-team/character-and-resilience-a-call-for-evidence/supporting_documents/Character%20and%20Resilience%20Call%20for%20Evidence.pdf [accessed 29 July 2019].

Department of Health. (2008). *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*. London: Department of Health. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf [accessed 30 August 2010].

Department of Health. (2015). *Future in mind. Promoting, protecting and improving our children and young people's mental health and wellbeing*. London: Department of Health. Retrieved from https://webarchive.nationalarchives.gov.uk/20170422110702/https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf [accessed 29 July 2019].

Department of Health/Department for Education (2017). *Transforming Children and Young People's Mental Health Provision: A Green Paper*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/664855/Transforming_children_and_young_people_s_mental_health_provision.pdf [accessed 29 July 2019].

Dietz, L. J., Stoyak, S., Melhem, N., Porta, G., Matthews, K. A., Walker Payne, M., & Brent, D. A. (2013). Cortisol response to social stress in parentally bereaved youth. *Biological Psychiatry*, *73*(4), 379–387.

Dowdney, L. (2000). Annotation: Childhood bereavement following parental death. *Journal of Child Psychology and Psychiatry*, *7*, 819–830.

Dyregrov, A. (1991). *Grief in children: A handbook for adults*. London: Jessica Kingsley.

Dyregrov, A. (2008). *Grief in children: A handbook for adults*. London: Jessica Kingsley.

Dyregrov, A., Gupta, L., Gjestad, R., & Mukanoheli, E. (2000). Trauma exposure and psychological reactions to genocide among Rwandan children. *Journal of Traumatic Stress*, *13*(1), 3–21.

Fauth, B., Thompson, M., & Penny, A. (2009). *Associations between childhood bereavement and children's background, experiences and outcomes: Secondary analysis of the 2004 Mental Health of Children and Young People in Great Britain Data*. London: National Children's Bureau.

Fattore, T., Mason, J., & Watson, E. (2016). *Children's understandings of well-being: Towards a child standpoint*. Dordrecht: Springer.

Fleming, S., & Balmer, L. (1991). Group intervention with bereaved children. In D. Papadatou, & C. Papadatou (Eds.), *Children and Death* (pp. 105–124). New York: Hemisphere.

Foley, P. (2001). Foreword: Children in society: Contemporary theory, policy and practice. In P. Foley, J. Roche, & S. Tucker (Eds.), *Children in society* (pp. 1–6). Basingstoke: Palgrave.

Foster, L., Woodthorpe, K., & Walker, A. (2019). From cradle to grave?: Policy responses to death in the UK. *Mortality*, *24*(1), 1–16.

Freud, S. (1917). Mourning and melancholia. In J. Strachey (Ed.), *On metapsychology: The theory of psychoanalysis* (pp. 251–267). London: Penguin.

Grinyer, A. (2012). A bereavement group for parents whose son or daughter died from cancer: How shared experience can lessen isolation. *Mortality*, *17*(4), 338–354.

Haine, R. A., Ayers, T. S., Sandler, I. N., & Wolchik, S. A. (2008). Evidence-based practices for parentally bereaved children and their families. *Professional Psychology, Research and Practice*, *39*(2), 113–121.

Harrington, R. (1996). Bereavement is painful but does not necessarily make children ill. *British Medical Journal*, *313*, 822.

Harrington, R., & Harrison, L. (1999). Unproven assumptions about the impact of bereavement on children. *Journal of the Royal Society of Medicine*, *92*(May), 230–232.

Harrison, L., & Harrington, R. (2001). Adolescents' bereavement experiences: Prevalence, association with depressive symptoms, and use of services. *Journal of Adolescents*, *24*, 159–169.

Heegaard, M. (1991). *When someone very special dies: Children can learn to cope with grief*. Minneapolis, MN: Woodland Press.

Hewison, A., Zafar, S., & Efstathiou, N. (2019). *Bereavement Support in the UK– a rapid evidence assessment*. Birmingham: Sue Ruder/University of Birmingham. Retrieved from www.sueryder.org/sites/default/files/2019-05/Sue%20Ryder%20Bereavement%20Support%20in%20the%20UK%20-%20University%20of%20Birmingham%20School%20of%20Nursing.pdf [accessed 29 July 2019].

Hindmarch, C. (1995). Secondary losses for siblings. *Child: Care, Health, and Development*, *21*(6), 425–431.

Holland, J. (2001). *Understanding children's experiences of parental bereavement*. London: Jessica Kingsley.

Irish Childhood Bereavement Network (2014). *Irish Childhood Bereavement Care Pyramid*. Retrieved from www.childhoodbereavement.ie/professionals/childhood-bereavement-care-pyramid [accessed 29 March 2015].

Jakobsen, I. S., & Christiansen, E. (2011). Young people's risk of suicide attempts in relation to parental death: A population-based register study. *Journal of Child Psychology and Psychiatry*, *52*(2), 176–183.

Katz, J. (2001). Introduction. In J. Hockey, J. Katz, & N. Small (Eds.), *Grief, mourning and the death ritual* (pp. 1–15). Buckingham: Open University Press.

Klass, D., Silverman, P. R., & Nickman, R. B. (1996). *Continuing bonds: New understandings of grief*. Washington, DC: Taylor & Francis.

Kobak, R., & Madsen, S. (2008). Disruptions in attachment bonds: Implications for theory, research, and clinical intervention. In J. Cassidy, & P. R. Shaver (Eds.), *Handbook of attachment: Theory, research, and clinical applications* (pp. 23–47). New York: Guilford Press.

Lee, N. (2001). *Childhood and society: Growing up in an age of uncertainty*. Buckingham: Open University Press.

Li, J., Vestergaard, M., Cnattingius, S., Gissler, M., Bech, B. H., Obel, C., & Olsen, J. (2014). Mortality after parental death in childhood: A nationwide cohort study from three Nordic countries. *PLoS Medicine*, *11*(7), e1001679.

Lytje, M., & Dyregrov, A. (2019). The price of loss – a literature review of the psychosocial and health consequences of childhood bereavement. *Bereavement Care*, *38*(1), 13–22.

Mayall, B. (1999). Children and childhood. In S. Hood, B. Mayall, & S. Oliver (Eds.), *Critical issues in social research* (pp. 10–24). Buckingham: Open University Press.

McLaughlin, C., Lytje, M., & Holliday, C. (2019). *Consequences of childhood bereavement in the context of the British school system*. Winston's Wish/University of Cambridge. Retrieved from www.winstonswish.org/wp-content/uploads/2019/06/COCB.pdf [accessed 26 July 2019].

McLoughlin, K. (2012). *Establishing a children's bereavement support network in Ireland: A scoping study*. Dublin: Irish Hospice Foundation. Retrieved from www.researchgate.net/publication/310564130_Establishing_A_Children%27s_Bereavement_Support_Network_in_Ireland_A_Scoping_Study [accessed 26 July 2019].

Mellor, P. A. (1993). Death in high modernity: The contemporary presence and absence of death. In D. Clark (Ed.), *The sociology of death* (pp. 11–30). Oxford: Blackwell.

Melvin, D., & Lukeman, D. (2000). Bereavement: A framework for those working with children. *Clinical Child Psychology and Psychiatry*, *5*(4), 520–539.

Moran, P., & Ghate, D. (2005). The effectiveness of parenting support. *Children and Society*, *19*, 329–336.

Monroe, B. (2013). Unpublished interview recording, 9 April, 2013, with Jane Ribbens McCarthy and Jeanne Katz, Open University UK.

Monroe, B., & Kraus, F. (1996). Children and loss. *British Journal of Hospice Medicine*, *56*, 260–264.

National Children's Bureau (2019). *Children's funding slashed by a third per child leaving thousands at risk of falling into crisis*. Retrieved from https://bit.ly/2m3963G [accessed 29 July 2019].

Neimeyer, R. A. (2001). *Meaning reconstruction and the experience of loss*. Washington, DC: American Psychological Association.

Neimeyer, R. A., Baldwin, S. A., & Gillies, J. (2006). Continuing bonds and reconstructing meaning: Mitigating complications in bereavement. *Death Studies*, *30*(8), 715–738.

NHS (2019). *NHS Long term plan*. Retrieved from www.longtermplan.nhs.uk [accessed 29 July 2019].

Oliviere, D. (2013). Unpublished interview recording, 9 April, 2013, with Jane Ribbens McCarthy and Jeanne Katz, Open University UK.

Parkes, C. M. (1975/2010). *Bereavement: Studies of grief in adult life* (4th ed.). London: Penguin.

Parkes, C. M. (1986). *Bereavement: Studies of grief in adult life* (2nd ed.). London: Routledge.

Parsons, S. (2011). *Long-term impact of childhood bereavement: Preliminary analysis of the British Cohort Study*. (BCS70) CWRC Working Paper. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/181353/CWRCN00081N2011.pdf [accessed 31 May 2019].

Paton, N. (2004). Dreamcatcher: Supporting bereaved children. *Nursing Times*, *100*(40), 24–25.

Pearce, C. (2019). *The public and private management of grief: Recovering normal*. London: Palgrave.

Pennells, M., & Smith, S. C. (1995). *The forgotten mourners: Guidelines for working with bereaved children*. London: Jessica Kingsley.

Penny, A. (2018). *Preparing the way: Evaluating support for children and young people before the death of someone important to them*. London: National Children's Bureau. Retrieved from www.childhoodbereavementnetwork.org.uk/media/91314/Preparing-the-way.pdf [accessed 24 July 2019].

Penny, A. & Rice, H. (2012). *Gaps in research*. Retrieved from www.childhoodbereavementnetwork.org.uk/research/gaps-in-research.aspx [accessed 31 May 2019].

Penny, A., & Stubbs, D. (2015). *Bereavement in childhood: What do we know in 2015?* London: National Children's Bureau.

Phillips, R., & Burt, M. (1999). *Rachel House: An independent evaluation. The views of children, young people and families*. Edinburgh: Children's Hospice Association, Scotland.

Pollock, L. (1983). *Forgotten children*. New York: Cambridge University Press.

Potts, S., Farrell, M., & O'Toole, J. (1999). Treasure weekend: Supporting bereaved siblings. *Palliative Medicine*, *13*, 51–56.

Prout, A. (2000). Children's participation: Control and self-realisation in British late modernity. *Children and Society*, *14*, 304–315.

Qvortrup, J. (1994). Childhood matters: An introduction. In J. Qvortrup, M. Bardy, G. Sgritta, & H. Wintersberger (Eds.), *Childhood matters: Social theory, practice and politics* (pp. 1–24). Aldershot: Avebury.

Ribbens McCarthy, J., & Jessop, J. (2005). *Young people, bereavement and loss: Disruptive transitions?* London: National Children's Bureau/Joseph Rowntree Foundation.

Ribbens McCarthy, J. (2006). *Young people's experience of loss and bereavement: Towards an interdisciplinary approach*. Maidenhead: Open University Press.

Rolls, E. (2007a). *Containing grief: Ambiguities and dilemmas in the emotional work of UK childhood bereavement services*. Unpublished PhD thesis, University of Gloucestershire.

Rolls, L. (2007b). *Mapping evaluations of UK childhood bereavement services. Final report to the Clara Burgess Charity*. Cheltenham: University of Gloucestershire.

Rolls, L. (2008). Helping children and families facing bereavement in palliative care settings. In S. Payne, J. Seymour, & C. Ingleton (Eds.), *Palliative care nursing: Principles and evidence for practice* (2nd ed., pp. 507–524). Buckingham: Open University Press.

Rolls, L. (2009). The ritual work of UK childhood bereavement services. In S. Earle, C. Komaromy, & C. Bartholomew (Eds.), *Death and dying: A reader* (pp. 175–183). London/Milton Keynes: Sage/Open University Press.

Rolls, L., & Payne, S. (2003). Childhood bereavement services: A survey of UK provision. *Palliative Medicine*, *17*, 423–432.

Rolls, L., & Payne, S. (2004). Childhood bereavement services: Issues in UK provision. *Mortality*, *9*(4), 300–328.

Rolls, L., & Payne, S. (2007). Children and young people's experience of UK childhood bereavement services. *Mortality*, *12*(3), 281–303.

Rolls, L., & Payne, S. (2008). The voluntary contribution to UK childhood bereavement services: Locating the place and experiences of unpaid staff. *Mortality*, *13*(3), 258–281.

Romonoff, B. D., & Terenzio, M. (1998). Rituals and the grieving process. *Death Studies*, *22*, 697–711.

Rowling, L. (2003). *Grief in school communities: Effective support strategies*. Buckingham: Open University Press.

Rowling, L., & Holland, J. (2000). Grief and school communities: The impact of social context, a comparison between Australia and England. *Death Studies*, *24*(1), 35–50.

Rutter, M. (1966). *Children of sick parents*. Oxford: Oxford University Press.

Ryan, F. (2015). *Mind the gap: How charities are mopping up after the government's failure to care*. New Statesman. Retrieved from www.newstatesman.com/politics/2015/02/mind-gap-how-charities-are-mopping-after-government-s-failure-care [accessed 31 May 2019].

Simpson, M. (2018). Social rights, child rights, discrimination and devolution: Untangling the web. *Journal of Social Welfare and Family Law*, *40*(1), 3–20.

Stokes, J. (2004). *Then, now and always*. Cheltenham: Winston's Wish.

Stokes, J. (2009). Resilience and bereaved children. *Bereavement Care*, *28*(1), 9–17.

Stokes, J., & Crossley, D. (1996). Camp Winston: A residential intervention for bereaved children. In S. Smith, & M. Pennells (Eds.), *Interventions with bereaved children* (pp. 172–192). London: Jessica Kingsley.

Stokes, J., Pennington, J., Monroe, B., Papadatou, D., & Relf, M. (1999). Developing services for bereaved children: A discussion of the theoretical and practical issues involved. *Mortality*, *4*(3), 291–307.

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

Sweeting, H., West, P., & Richards, M. (1998). Teenage family life, lifestyles and life chances: Associations with family structure, conflict with parents, and joint family activity. *International Journal of Law, Policy and the Family*, *12*(1), 15–46.

Thompson, F. (1995). *'Where is dead?' A study of bereaved children's questions to doctors*. Unpublished MSc. thesis. University of Southampton.

United Nations. (1989). *United Nations convention on the rights of the child*. Geneva: United Nations.

Valentine, C. (2006). Academic constructions of bereavement. *Mortality*, *11*(1), 57–78.

Walter, T. (1994). *The revival of death*. London: Routledge.

Walter, T. (1996). A new model of grief: Bereavement and biography. *Mortality*, *1*(1), 7–25.

Weakes, L. (2015). *Improving mental health: Recognising the vital role of charities*. The Kings Fund. Retrieved from www.kingsfund.org.uk/blog/2015/05/improving-mental-health-recognising-vital-role-charities [accessed 31 May 2019].

Wickham, S., Anwar, E., Barr, B., Law, C., & Taylor-Robinson, D. (2016). Poverty and child health in the UK: Using evidence for action. *Archive of Diseases in Childhood*, *101*(8), 759–766. Retrieved from https://adc.bmj.com/content/101/8/759 [accessed 31 May 2019].

Wilcox, H. C., Kuramoto, S. J., Lichtenstein, P., Långström, N., Brent, D. A., & Runeson, B. (2010). Psychiatric morbidity, violent crime, and suicide among children and adolescents exposed to parental death. *Journal of the American Academy of Child and Adolescent Psychiatry*, *49*(5), 514–523.

Williams, J., Chaloner, J., Bean, D., & Tyler, S. (1998). Coping with loss: The development and evaluation of a children's bereavement project. *Journal of Child Health Care*, Summer, *2*(2), 58–65.

Worden, J. W. (1996). *Children and grief: When a parent dies* (3nd ed.). New York: Guilford Press.

Worswick, J. (2000). *A house called Helen: The development of hospice care for children*. Oxford: Oxford University Press.

Yule, W., & Gold, A. (1993). *Wise before the event: Coping with crises in schools*. London: Calouste Gulbenkian Foundation.