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**UK CHILDHOOD BEREAVEMENT SERVICES: A REFLECTION ON THEIR DEVELOPMENT AND  
CULTURAL INFLUENCE**

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# **UK CHILDHOOD BEREAVEMENT SERVICES: A REFLECTION ON THEIR DEVELOPMENT AND CULTURAL INFLUENCE**

## **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 well-being. 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.

## **Key words**

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

# UK CHILDHOOD BEREAVEMENT SERVICES: A REFLECTION ON THEIR DEVELOPMENT AND CULTURAL IMPACT

## 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 (Note 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 well-being 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 features should be respected, and that each person [has] to resemble a conventional model, an ideal type' (Ariés, 1962: 415, quoted in Corsaro, 1997: 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 and 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' (Allred, 1998: 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: 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 and 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 et al., 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 20<sup>th</sup> 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: 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 et al., (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 and 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 having diminished, the deconstruction of shared rituals can result in the deterioration of *meaning* (Romonoff and Terenzio,1998) – a dimension considered important in bereavement (Neimeyer, et al., 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 and Harrison, 1999), this event is seen as an important determinant for adult psychiatric health (Lytje and Dyregrov, 2019)? Whilst 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 and 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 and Payne, 2007). Other studies implicate childhood bereavement in (amongst others) serious illness (Worden, 1996; Fauth et al., 2009); higher mortality risk (Li et al., 2014); increased risk of negative health behaviours (Sweeting et al., 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 and 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, 1991:320, 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 and 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 with Jessop, 2005);
- The circumstances around the death, including how the person died (Dietz et al., 2013), whether it occurred suddenly or anticipated, how and what children are told, and if and how involved they are involved in the funeral (Harrison and 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: 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: 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 and Payne, 2007), and their subsequent relationships with peers and school (Ribbens McCarthy and 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 amongst 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 these data are 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 and 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 on-going 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 ‘free-standing’ 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, whilst a further 30% (27) had begun during the period 1998 to 2000 (Rolls and 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 and 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**

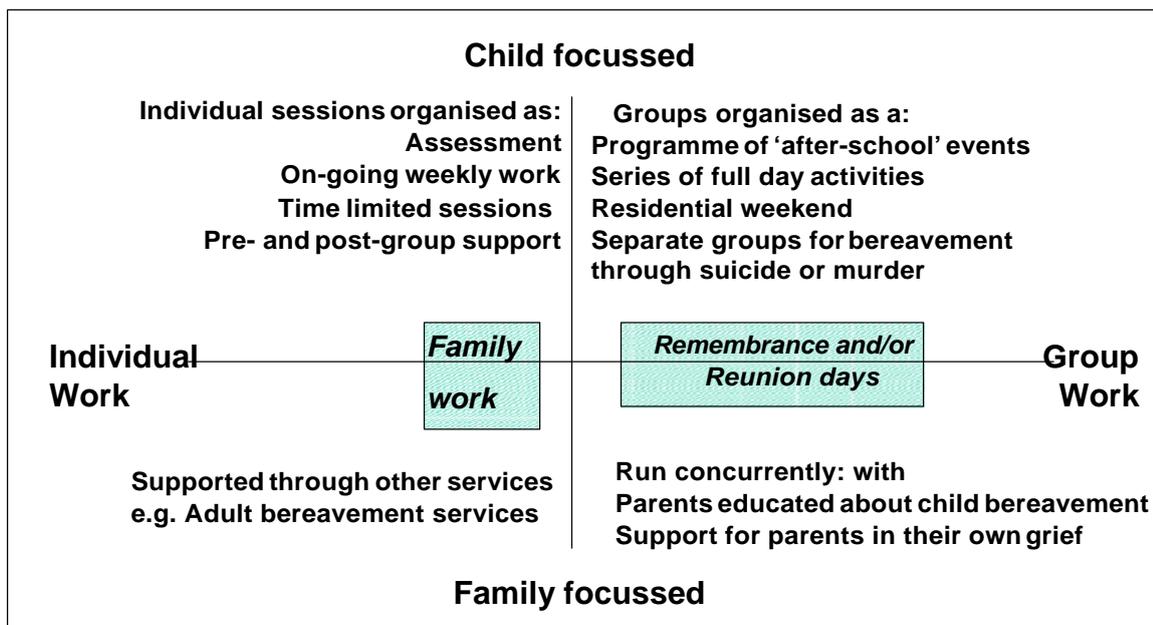


Figure 1: Range of direct service provision (Rolls and Payne, 2004).

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 and Payne, 2004). For some, this has resulted in post-traumatic growth (Brewer and Sharpe, 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, 2103), 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).

Whilst 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 the Figure 2.

**Figure 2**

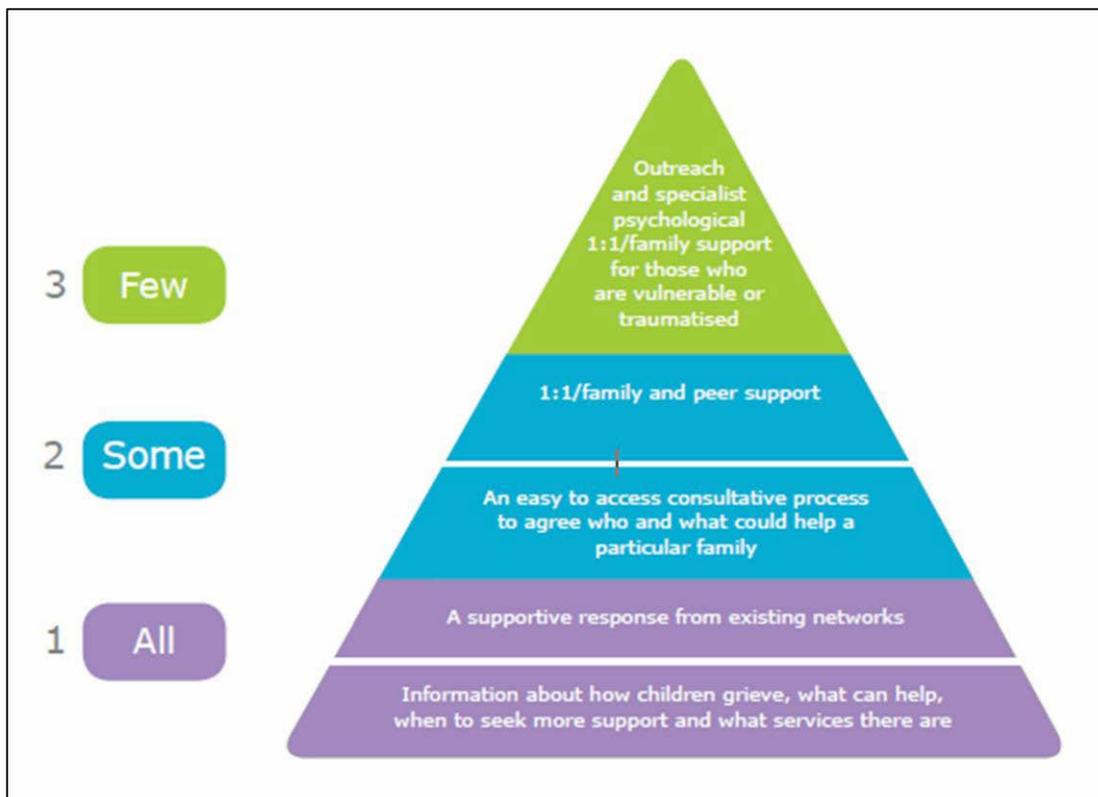


Figure 2: What good provision for bereaved children and young people and their parents and carers looks like (Childhood Bereavement Network, undated).

## 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 and Urbanowitz, 1987; Pennells and Smith, 1995; and Worden, (1996) followed by - amongst others – Christ, 2000; and Dyregrov, et al., 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, 12.01). 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 and 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 (Coultrick, 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 (e.g. Monroe and Kraus, 1996); the practical issues involved in developing services (e.g. Stokes et al., 1999; Melvin and Lukeman, 2000; Worswick, 2000); types of interventions that services use (e.g. Fleming and Balmer, 1991; Thompson, 1995; Stokes and Crossley, 1996; Potts et al., 1999; Paton, 2004); and the development of assessment tools for childhood bereavement services (e.g. Birenbaum, 2000); as well as the results of evaluations of a particular service (e.g. Williams et al., 1998; Phillips and Burt, 1999). There had also been a review of services available in the UK for children who had been bereaved (e.g. Blanche and Smith, 2000) as well as a more recent review of the impact and educational outcomes of childhood bereavement services (e.g. Ackerman and Statham, 2014). Despite this extensive and extending literature, the work of Rolls and Payne (2003; 2004; 2007; 2008; and Rolls, 2007a; Rolls, 2009) 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 and 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), whilst 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 (see Note 2) as a special interest group concerned with encouraging Bereavement Research into Practice.

The second and most significant network - the Childhood Bereavement Network (CBN) (see Note 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 (see Note 4). The current 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 to 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 (see Note 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 et al., 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 et al., 2004; Simpson, 2016). However, Foster et al., (2019:12) 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, whilst local lobbying and advocacy has resulted in the commissioning of a childhood bereavement service by Leeds City Council. At national level, CBN have 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, whilst 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, the '*Future in mind*' (Department of Health, 2015) is concerned with the prevention/promotion of resilience, prevention and early intervention, and the *Character and resilience: A call for evidence* (Department of 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 policies 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 et al., 2019: 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 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) have 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 on-going 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 and Payne, 2004).

Whilst 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 and 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 – have developed a suite of outcome measures specifically for childhood bereavement services (see Note 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 et al., 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 well-being 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 and Payne, 2007; Stokes, 2009; Brewer and Sparkes, 2011b). Whilst 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 and 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 and Sharpe, 2011a). Importantly, services act as a parenting support service (Moran and Ghate, 2005) in which parents are supported not just on their own account, but also in parenting their bereaved child (Rolls and 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 et al., 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: 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 and Sharpe, 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 et al., 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) (see Note 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.

Figure 3

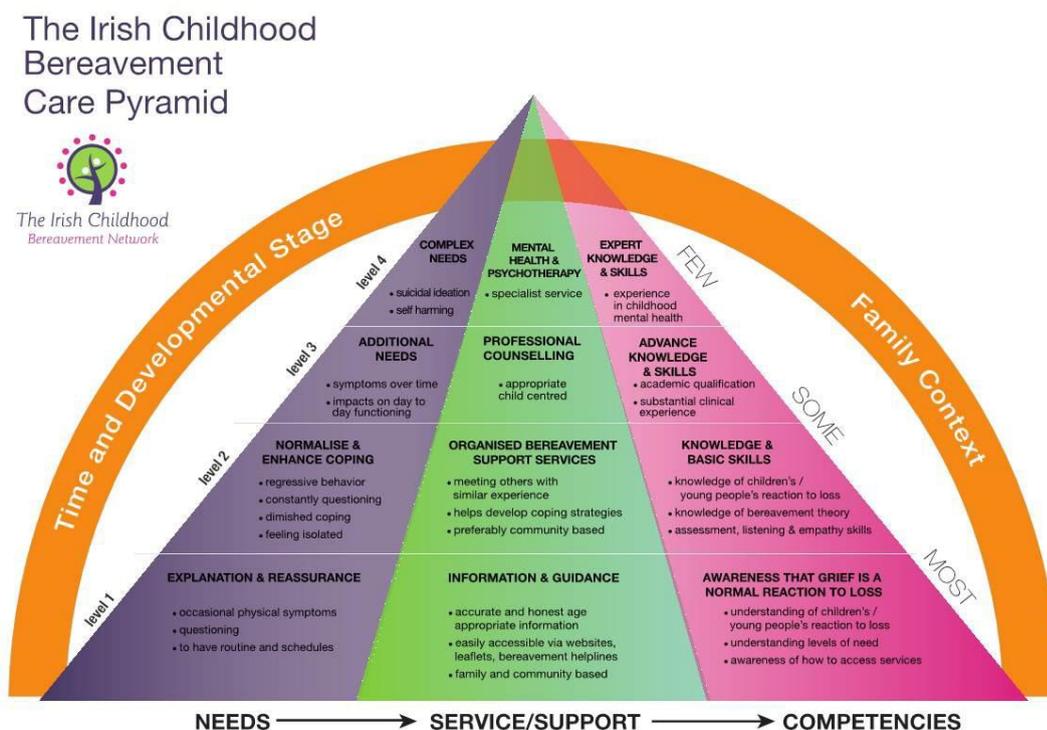


Figure 3: The Irish Childhood Bereavement Care Pyramid (ICBN, 2014).

## 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, 1992:194), 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; 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).

#### Notes

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

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 <http://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: [https://www.cruse.org.uk/sites/default/files/default\\_images/pdf/Documents-and-fact-sheets/Bereavement\\_Care\\_Service\\_Standards.pdf](https://www.cruse.org.uk/sites/default/files/default_images/pdf/Documents-and-fact-sheets/Bereavement_Care_Service_Standards.pdf)

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

6. For more information about the Irish Childhood Bereavement Network see: <https://www.childhoodbereavement.ie>

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