



The Changing Value of the Child – A Review of the Literature Regarding Social Perceptions of Sick and Dying Children

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Abstract

This article reviews the literature pertaining to the changing value of the child in England since the 19th century, highlighting the relative policy neglect of contemporary sick and dying children. The review discusses the relationship between the value of the child, social constructions of childhood and social policy. The review demonstrates how the value of the child has altered from one of utility to a contemporary position of sacralisation, illustrated by mortality statistics as a measure of associated policy impact. However, large reductions in mortality rates conceal the more complex picture of contemporary child health. Children die each year from life-limiting and life-threatening disorders. Moreover, technological developments increasingly allow children to live longer with such conditions, albeit with ever more complex ill health. Such children are therefore dying over protracted periods of time. However, they are largely absent from policy, which tends towards standardised outcome measures which may not reflect the needs of this minority group. Therefore, although contemporary constructions of childhood focus upon sacralisation, reflecting psychological value to parents and society, the most vulnerable child members of society remain neglected in policy and service provision.

Introduction

Death in childhood in contemporary England is unusual. This achievement has been supported through policies to improve the health and well-being of children, and mortality data provide an important measure of policy impact. Child policy development is contextualised to societal views of childhood and children. The trend in the social construction of childhood in England over time has been towards increasing standardisation and sacralisation: children are perceived as vulnerable, and childhood provides a time of development towards adult potential and productivity (Qvortrup 2010; Wyness 2006). Children may not be valued as ‘human beings’ so much as ‘human becomings’ (Qvortrup 2005).

Perceptions of the value of children, held by society and parents, are important components in social constructions of childhood. Children may be valued for their utilitarian contribution to society or for the psychological benefits they bring parents (Jones and Brayfield 1997; Hoffinan and Hoffman 1973). In either case, analysis of social policy illustrates how childhood is constructed to maintain both the well-being and the future utility of children. However, some children still die, and current paradigms concerning the value of children and the social construction of childhood may exclude that group. The value to society of the child who may not live and who cannot achieve developmental ‘norms’ becomes questionable and may explain their relative absence from policy.

Analysis of mortality data in isolation provides a misleading sense of the contemporary state of child health. Whilst death in childhood continues to reduce over time, scientific developments enable children to survive increasingly complex illnesses (Fraser et al. 2011). Therapeutic

innovations enable children to live longer, but with increased ill health (Craft and Killen 2007). In other words, mortality in childhood is reducing, but morbidity is increasing, associated with physical and intellectual impairment (Fraser et al. 2011).

The nature of life-limiting and life-threatening disease is that, in the absence of curative options, death is inevitable. Thus, children with life-limiting and life-threatening disorders in the 21st century may be dying over a prolonged period of time and simultaneously living with extensive physical and/or intellectual impairment (Craft and Killen 2007). Dying children therefore do not easily fit social constructions of childhood based upon 'human becomings', for which policy and outcome measures utilise standardised developmental 'norms' which may not reflect difference associated with physical or intellectual impairment.

For dying children, survival itself, and therefore their potential as 'human becomings', is threatened. Their relative absence from policy, combined with the overarching agenda of 'human becoming', means that the nature of their 'being' also remains largely unaddressed, either with respect to validation of their life experiences or in terms of public services delivery. The value of these children to society, both in their living and their dying, is unrecognised and even delegitimised (Todd 2007).

Since 2007, there has been a surge of state interest in children's palliative care provision in England. A relatively new health/social care speciality, services have hitherto been provided through the voluntary sector in the main (Craft and Killen 2007). Following an independent review of services and a statistical review of care and mortality (Craft and Killen 2007; Cochrane et al. 2007), recommendations for future service development have been set out (DH 2008). Meanwhile, a state review of funding for the sector is currently being undertaken, and an analysis of morbidity data has revealed that the prevalence of life-limiting and life-threatening disease in children has increased from 25 per 10,000 in 2001 to 32 per 10,000 in 2010 (Fraser et al. 2011). This article considers the absence of dying children from contemporary social constructions of childhood in England, particularly with respect to the value of such children to parents and society. I argue that this absence compromises the development of effective social policy for this minority group.

The review will provide a brief summary of changes in mortality rates in England from the 19th century to the current time. An analysis of policy developments will follow, illustrating: (i) the ways in which social policy both influences and is influenced by mortality; and (ii) the relationship between social policy, social constructions of childhood and the value of children. Whilst acknowledging the complex interplay of competing political, class, technological and philanthropic agendas, the review is structured around distinct areas of development rather than a strict chronology of developments. Finally, the review will refocus upon dying children and the ways in which standardised approaches to childhood, supported by social policy, contribute to the marginalisation of this minority group. The review will conclude that policy and practice fail to address the needs of dying children and their families and reflect societal ambivalence and lack of value for this growing minority population.

Child and infant mortality

Mortality rates reflect life expectancy and health (Pickvance 2007). Mortality statistics are therefore also a helpful gauge of the usefulness of social policy (Haines 1995). Since the 19th century, mortality in childhood has decreased, associated with improved provision in health, education and welfare (Dean 2007). National statistics record mortality in childhood as a measure of deaths occurring at specific age ranges: neonatal (less than four weeks of age), infant (less than a year of age) and child (over 1 year to a specified maximum age). More details can be found at National Statistics Online (www.statistics.gov.uk/default.asp).

Infant mortality data demonstrate dramatic reductions over time. Data from 1896 give a rate for infants of 148 deaths per 1000 live births (Haines 1995). In 1921, the rate had declined to 82.8 per 1000 (ONS 2010). By 2009, the rate in England and Wales was 4.5 deaths per 1000 (ONS 2011). Child mortality data illustrate that steady reductions continue: between 1980 and 2009, the rate dropped from 31 to 12 per 100,000 (ONS 2011). Overall, childhood mortality rates have reduced since the 19th century (Haines 1995). This is associated with improvements in health technology, including vaccination programmes and hospital developments, and developments in employment, housing, nutrition and education which contributed to improved health and well-being for children (Szreter and Woolcock 2004). However, the declining total rates mask some significant variations according to geography (rural or urban) and socio-economic status (Szreter and Woolcock 2004). That mortality and ill health continue to have an inverse relationship with socio-economic status is well reported (Acheson 1998; Black 1980). However, the contemporary position is that childhood death rates have continued to decrease, and neonatal rates have stabilised.

Infant and child mortality have multiple factors of influence; it is difficult to accurately attribute cause and effect because of the complex interplay between issues (McKeown and Record 1962). By the late 19th century, birth rates had slowed, whilst mortality, particularly amongst infants, remained high (Davin 1978). This was associated with rapid urban expansion coupled with inadequate sanitation and poor standards of living for the working class (McKeown and Record 1962; Davin 1978; Leon 2008). Overcrowding and inadequate hygiene facilitated the spread of infectious disease, and poor nutrition limited disease resistance (Davin 1996; McKeown and Record 1962).

Meanwhile, those with the voting power to bring about welfare and infrastructure development tended to resist the burden of taxation, limiting the impact of early public health legislation (Szreter and Woolcock, 2004). Increased philanthropic and religious influence, recognition of the value to private business of improving the urban infrastructure and improved voting rights for numbers of working-class men enabled funding for sanitation and sewerage which reduced exposure to some pathogens (McKeown and Record 1962; Szreter and Woolcock 2004). Improved medical knowledge, the identification of pathogenic organisms and development of treatments facilitated further declines in mortality associated with infection into the 20th century (McKeown and Record 1962). Such developments were significant in the decline in overall childhood mortality. However, this complex problem can be in part aligned with changes in social constructions of childhood, the value of children and associated development in social policy

Mortality data, social policy and social constructions of childhood

There is some debate concerning when society began to differentiate childhood as a life stage. Ariès (1978) considered the 18th century to herald this change in perspective, but others, including Zelizer (1994) and Moran-Ellis (2010), date the change to the 19th century. However, there is agreement that the change relates to increased protection of children, associated with developments in how children are valued, and illustrates changing social constructions of childhood (Ariès 1978; Davin 1999; Moran-Ellis 2010; Zelizer 1994). Social constructions of childhood have varied over time in terms of age and experience boundaries (Davin 1999).

During the 19th century, mortality rates were high, but marriage rates increased and marital age lowered: increased birth rates led to the population having a greater proportion of children rather than being dominated by adults (Cunningham 1990). The 19th century childhood was determined by geography and social class. Geography tended to dictate the type of work to which children were exposed: rural children might work in the home, fields or with livestock;

urban children were more likely to undertake industrial work or domestic employment (Cunningham 1990; Hendrick 1997b). However, the likelihood of employment was dictated by social class as a measure of poverty or wealth: working-class children worked; upper-class children were cared for by servants (Davin 1999).

In rural areas, employment opportunities did not increase (Cunningham 1990), and perceptions of juvenile delinquency increased as adults felt threatened by the increasing numbers of children (Thorne 1987). Meanwhile, industrialisation facilitated the visible movement of large numbers of urban children into the workplace, but in harsh environments such as mines and factories (Davin 1999). The potential for child exploitation rose (Cunningham 1990). The rapid social changes brought about by industrialisation challenged perceptions of family and family life, prompting moral panic, and galvanising action to protect children (Piper 2005). However, attitudes towards children and childhood were ambivalent, driven by a combination of philanthropic and market-driven concerns. Unease about the welfare of child workers sat alongside the economic imperative to maintain their presence and moral concerns about the activities of unemployed children: increased scrutiny and regulation of children's lives through education, health, labour and criminal justice policy was the outcome (Moran-Ellis 2010).

Philanthropic concerns for vulnerable, poor children led to increased advocacy on their behalf for employment legislation (Piper 2005). The legal age of employment increased from 10 years in 1874 to 12 years in 1901 (Davin 1999). In addition, specific legislation to structure work increasingly in favour of child protection in mines, factories and shops was passed between 1887 and 1900 (Piper 2005). Alongside such legislation limiting children's participation in the workplace, developments in education also contributed to the protectionist attitude towards children. Education was made compulsory with the 1870 Education Act, and successive legislation until 1918 raised the school leaving age from 10 to 14 years, with personnel employed to enforce the new laws (Davin 1996; Hendrick 1997a). However, compulsory education illustrated state ambivalence towards children: a compassionate stance towards rescuing them from exploitation was counterbalanced by the perception of threat from working-class children who needed to be civilised (Davin 1996; Davin 1999). Crucially, however, such reform challenged parents' capacity to determine their own child's upbringing (Piper 2005). For example, the laws required payment by parents for compulsory education whilst simultaneously undermining the utilitarian value of the child to the family (Davin 1996).

Whilst protectionist attitudes and high mortality were influential in social policy developments, societal ideas about the family simultaneously became a dominant influence (Hendrick 1997b; Moran-Ellis 2010; Thorne 1987). Arising from middle-class notions of domesticity, motherhood and work, these shaped the concept of childhood and its relationship with employment, education and child health (Hendrick 1997b). Meanwhile, paternalist, professional and feminist agendas contested the validity of making public the private domestic world and its childrearing and family characteristics (Koven and Michel 1990). Ultimately, the 19th and early 20th centuries saw an unprecedented rise in professional roles associated with childhood, including medicine, psychology, education and social work (Davin 1999). This fulfilled the professional desire to supervise childrearing and motherhood, supported by philanthropist women for whom the cause represented a route into public life and influence which disenfranchisement prevented (Koven and Michel 1990). Such specialisation of childhood began to standardise the experience through increased theorising, scrutiny and monitoring of child health, development and welfare (Hendrick 1997a; Moran-Ellis 2010).

As well as monitoring of the vulnerability of children in the workplace, increasing professional intervention in childhood facilitated greater scrutiny of the domestic environment (Piper 2005). Between 1876 and 1897, specific concerns arose with a rise in infant mortality against a backdrop of generally reducing childhood mortality (Hendrick 2005). This was linked

to inadequate childcare, often provided by 'baby farmers' – women paid to nurse infants – as well as notions of inadequate parenting (Amot 1994; Grey 2009; Piper 2005). Whilst the focus of scrutiny was childrearing and mothers, various other debates were being played out. Keeping working-class women at home instead of at work, undermining their skills as mothers and promoting intervention, often by philanthropic women, supported (i) nationalist concerns for the health, growth and strength of Britain; (ii) anxieties regarding urbanisation and changes to the powerbase of wealthy land owners; (iii) class debates about parliamentary inequalities and the enfranchisement of the working class; and (iv) the creation of a role for women who sought greater public recognition (Koven and Michel 1990; Amot 1994; Grey 2009). Specific legislation was passed concerning child protection, including the 1872 and 1889 Infant Life Protection Acts and the 1889 Prevention of Cruelty to Children Act (Hendrick 1997a). The Industrial Schools Acts (1857–1889) facilitated the removal of children from the family home to enable state intervention in their moral welfare (Piper 2005). Provision of school meals and school health services sought to counterbalance neglectful parenting (Hendrick 2005).

However, philanthropic and state concern for the child was balanced against state interest in securing a future population who were morally sound and appropriately socialised so that they could maintain future national interests and security (Piper 2005). Rising birth rates during the 19th century had increased the proportion of children to adults; this fuelled fears of delinquency, particularly in rural areas where child employment was more limited (Cunningham 1990). Criminal justice legislation accordingly became more focused upon the problem of youth crime and the threat to social order posed by children (Thorne 1987).

Social policy developments during industrialisation meant that the early 20th century was characterised by improved standards of living and reduced mortality rates (Hendrick 2005). Mortality rates continued to decline associated with ongoing expansion in health policy and technology (Hendrick 2005). Regulation of childhood continued, with increasing state clarification of the role of 'family' to nurture and cherish children (Moran-Ellis 2010). Greater direction was provided through law, medicine and education, influenced by politics and culture (Hendrick 1997b). Evacuation during World War II revealed deprivation amongst certain groups of children, leading to increased welfare provision (Hendrick 1997a). Furthermore, the work of Bowlby (1968, 1973) stressed the importance of mothering in early childhood, and provided a long term focus for child development and parenting policy and practice. A new perspective developed on parenting, emphasising the significance of nurture and bonding, the emotionality of parenting and parental responsibilities – inadequate parenting could harm a child.

Birth rates reduced, leading to a smaller proportion of children to adults (Davin 1999). However, policy progression in health, education and criminal justice can still be linked to moral panics concerning children, consistently linked to competing notions of the child as threatened or threat (Thorne 1987). Thus, during the 1950s and 1960s, emerging youth cultures, such as mods and rockers or hippies, raised concerns about the threat posed to moral order (Thorne 1987). More contemporary criminal justice developments, such as Anti-Social Behaviour Orders (ASBOs) governed by the Anti-social Behaviour Act of 2003, continue to emphasise the threat that young people pose to society (Eadie and Morley 2007; Furlong and Cartmel 2007).

However, ambivalence persists. Young people's activity is increasingly restricted, from the perspective of needing to protect society from this group. Using a range of policies, from prolonging the age of compulsory education to criminalising anti-social behaviour, the state responds to a socially constructed perception of threat arising from this age group (Furlong and Cartmel 2007). Concurrently, children are ever increasingly protected and monitored. The Children Act of 1989 emphasised children's rights and parental responsibilities (Moran-Ellis 2010). There is increasing state intervention to maintain children's safety, even a notion that parents

are unable to do so in an era of ever-increasing technology (Vincenten and Michalsen 2002). Play is restricted as a response to perceptions of threat to child safety (Valentine and McKendrick 1997). The standardisation of educational curricula and increasing measurement of achievement attempt to increase educational opportunity for those not well represented, through barriers of class or race for example (Furlong and Cartmel 2007). Meanwhile, the National Service Framework for Children, Young People and Maternity Services (DH 2004) and Every Child Matters programme (DfES 2004) identify standards for improvements in the health and well-being of children through increased scrutiny of health, safety, enjoyment and achievement, positive contribution and economic well-being.

State responses through policy to protect children, intervene in and standardise childhood and produce useful future citizens illustrate the complex relationships between policy, mortality rates and social constructions of childhood (Dean 2007; Moran-Ellis 2010). Children have alternately been perceived as vulnerable from or a threat to society. This ambivalence may be associated with society's perceptions of the value of children and the ways in which that may be measured. The traditional measure was one of utility (Cunningham 1990), but increasingly, the trend has been psychological and social worth (Hoffman and Hoffman 1973).

The Value of Children and societal ambivalence: human beings or human becomings?

Notions of the value of children have progressed from a greater emphasis on utilitarian value to one which recognises the psychological and social needs they fulfil for parents (Hoffman and Hoffman 1973). The evidence for this relies upon limited numbers of personal diaries and research based upon historical developments in policy and welfare provision, the measurement of which have been inconsistent over time (Cunningham 1990; Szreter and Woolcock 2004). As such, it provides a perspective on children which is reflective more of their value to society than to parents (Jones and Brayfield 1997). However, this perspective is useful, since it reflects the social and policy context within which children are raised.

In the past, the value of children was associated with economic measures: the child's contribution to family or societal productivity. Prior to industrialisation, the agrarian economy, as in developing nations today, emphasised the utility of children and their contribution to family economics (Jones and Brayfield 1997). During industrialisation, children's participation in paid work and generating family income was prioritised (Cunningham 1990; Thorne 1987). In both of these examples, the value of the child to the family unit is economic. However, societal notions of the economic value of children are also influential and are demonstrated in policy developments.

In the 19th century, policies which regulated child labour were protective; however, they also served to ensure their continued presence in the labour force, reflecting the economic value of children to society (Thorne 1987; Wyness 2006). Likewise, changes to education policy over time look to the future usefulness of children rather than purely benevolent outcomes (Moran-Ellis 2010). The contemporary emphasis within this perspective is upon the utilitarian value of children to *society* rather than parents (Jones and Brayfield 1997; Wyness 2006). However, emerging concerns about the impact of longevity and decreases in the proportion of children to adults have refocused the debate upon the utilitarian value of children to both society *and* parents (Oldman 1990). In each of these examples, the purpose of social policy for children and the social value of children may be seen as the development of healthy, educated adults who can function effectively for the benefit of society in the future (Qvortrup 2010; Wyness 2006). Children are viewed less as human beings and more as 'human becomings' (Qvortrup 2005).

The utilitarian value of children has, however, been challenged. As children's lives have become increasingly institutionalised and regulated, their economic worth has reduced so

that 'their cost far exceeds their practical worth' (Hoffman and Hoffman 1973, 19). Alternative ways of measuring the value of children have been developed. Stemming from concerns about fertility, research was undertaken in the 1970's to clarify the intrinsic purpose for parents of having children (Trommsdorf and Nauk 2010). A conceptual scheme of parental needs fulfilled by children was developed and tested in countries across the world (Hoffman and Hoffman 1973; Hoffman and Manis 1979; Kagitcibasi 1982; Nauk and Klaus 2007; Trommsdorf et al. 2005; Trommsdorf and Nauk 2010).

The model identified nine categories of value; significantly, the economic value of children was incorporated but distinguished from psychological-emotional values, such as social identity, expansion of self, power, stimulation and morality (Hoffman and Hoffman 1973). Questions have been posed regarding the model's comprehensiveness: it was developed from existing research using inductive methods and retains a psychology bias (Nauk 2005). Furthermore, testing of the model has been criticised for producing culturally specific results (Trommsdorf and Nauk 2010). However, validation of the model has progressed through cross-cultural studies simultaneously testing the model, or variants of it, in multiple countries (Kagitcibasi 1982; Nauk and Klaus 2007) or across generations in a single country (Mayer et al. 2005).

Criticisms of the Value of Children model do not detract from its usefulness as a tool for broadening understanding of the variety of ways a child's value may be measured, particularly since procreation continues when children are no longer needed for their utilitarian benefits (Hoffman and Hoffman 1973). Whilst England is not a country in which the Value of Children model has been tested, similarly developed western countries, such as the United States and other European countries, have been included, which suggest that the findings may be somewhat transferable.

More recent developments of the Value of Children study have led to a model based on three aspects: self-esteem, affect and comfort (Nauk and Klaus 2007). Testing of this new tool demonstrates that emotional values are *consistently* highly rated across different cultures, whereas self-esteem and comfort are specifically correlated with fertility and affluence (Nauk and Klaus 2007). Similarly, affect is emphasised in a cross-generational study of a variant of the Value of Children study based in Germany (Mayer et al. 2005). The value of children seems to have altered over time: grandmothers have a clearer focus on the economic utility value of children compared with a greater emphasis upon emotional value for younger mothers (Mayer et al. 2005). Alternative research, in which England has been included, has likewise concluded that the value of children is now more readily described in terms of psychological and social measures than economic utility terms (Jones and Brayfield 1997).

Jones and Brayfield (1997) used international social survey data from Austria, Britain, Ireland, Italy, the Netherlands and West Germany to analyse attitudes towards childrearing. The study identified the phenomenon of pronatalism (positive feeling about raising children and children themselves) and how it varied in industrial and rural economies. Pronatalism was considered less rational in industrialised economies, since childrearing was not required for economic benefit: the economic value of children in industrialised societies is low (Jones and Brayfield 1997). This research substantiates the Value of Children studies, emphasising the idealisation of childrearing across nations and the associated psychological values conferred upon parents through children (Jones and Brayfield 1997). In clarifying the centrality of affect, or emotion, in the value of children to parents, the work of Jones and Brayfield (1997) supports the notion that children have become 'sacralised' (Zelizer 1994).

Sacralisation refers to 'objects being invested with sentimental or religious meaning' and has been used in the development of a theory of the changing value of American children through history (Zelizer 1994, 11). Although that theory is focused upon America, its historical origins mirror the pattern of developments in social policy and child welfare in England. Zelizer links

price and value: noting the declining economic value of children, she considers how this change relates to cultural developments in family and social class (Zelizer 1994). In this respect, her work sits well with the Value of Children approach, since both are concerned with understanding values of children which are broader than economics (Hoffman and Hoffman 1973; Zelizer 1994). Zelizer (1994, 2009) concludes that 'the twentieth century economically useless but emotionally priceless child displaced the nineteenth century useful child'. In other words, contemporary parenting is associated with emotional fulfilment rather than economic comfort.

The value of children across countries and cultures can be measured both in economic and sentimental terms. A combination of cultural and structural influence, through policy and increased institutionalisation, has contributed to somewhat ambivalent social perspectives on childhood, whereby children are seen as both victims and threats (Hendrick 2005; Moran-Ellis 2010). Changes in employment, education, health and criminal justice since the 19th century have polarised perspectives on childhood so that contemporary Western children are valued more for their emotional worth than their economic utility (Hoffman and Hoffman 1973; Jones and Brayfield 1997; Zelizer 1994).

Contemporary social constructions of childhood emphasise state and parental surveillance, control and sacralisation of children as a predominant context for parenting in the 21st century (Moran-Ellis 2010; Zelizer 1994). Parents are held responsible for their child's well-being and development along a state-defined, standardised pathway, which is increasingly scrutinised (Moran-Ellis 2010). This is the social context in which the parents of dying children must raise their children.

The value of dying children in the 21st century

Although childhood mortality is at a record low, some children still die. 3,924 children died in England in 2005 from disorders such as congenital malformation, chromosomal abnormality, cancer and diseases of the nervous system, all of which might be described as life-limiting and life-threatening disorders (Cochrane et al. 2007). Such disorders are liable to cause significant morbidity as well as childhood mortality, particularly as developments in technology enable children to survive increasingly complex ill health (Craft and Killen 2007). Estimates of the prevalence of life-limiting and life-threatening illness in children suggest that numbers of children living with such diagnoses have increased yearly from 2000–2010 (Fraser et al. 2011). However, this group has been generally under-represented in policy.

Contemporary social constructions of childhood incorporate parenting to support a child grow and develop into independence, underpinned by social policy in education, health, work and criminal justice. Parents of dying children face uncertainty about their child's health and its longevity, but the certainty that death is inevitable (Hutchinson et al. 2003). Many parents living with dying children will be doing so for protracted lengths of time, albeit that the child is not 'actively dying' throughout, but that the terminal nature of the disease is acknowledged from the outset (DH 2008). Contemporary social policy focuses upon scrutiny and measurement of child health and development along standardised pathways. Yet, the life experience of dying children and their parents cannot measure up to such policy demands.

Dying children may remain dependent upon others beyond developmental 'norms', and their attainment of developmental milestones may be compromised (Craft and Killen 2007). Such norms and milestones and their developmental psychology roots may be characterised as oppressive, problematising difference and promoting exclusion (Goodley and Runswick-Cole 2010; Goodley and Runswick-Cole 2011b). Many dying children experience physical and intellectual impairment (Craft and Killen 2007). Such children have been somewhat neglected in policy, linked to the medical model of viewing disability as a problem with an

individual (Dean 2007). The social model of disability attributes individual social exclusion to society's inability to accommodate difference, therefore classifying disability as a social construction (Davis et al. 2005). Indeed, it is well documented that families with disabled children are more likely to experience poverty and social exclusion (Beresford 1995; Dobson 1998; Kagan et al. 1998).

Access to universal services may be limited, at both policy and operational levels and making special provision for disabled children risks excluding them from the mainstream (Read et al. 2012). However, it is not clear that generic policy is adequate for disabled or dying children. The Every Child Matters programme (DfES 2004) was established to reform children's services, ensuring that education, health and social care were provided in an integrated manner and according to prescribed outcomes for children. Every Child Matters identifies five foci: health, safety, enjoyment and achievement, positive contribution and economic well-being (DfES 2004). However, the outcome measures for each area are based upon socially constructed social, cultural, developmental and moral norms which arguably disregard the impact of physical or intellectual impairment (Goodley and Runswick-Cole 2011a). It may not be possible to gauge the 'achievements' of children with progressive or degenerative conditions using typical measures (Sloper et al. 2009).

In general, children are expected to conform to social life and policy which provides little recognition of individuality (Mayall 2006). Since 2006, campaigners have sought equal recognition in policy and services for children with disabilities under the banner of 'Every Disabled Child Matters' (EDCM 2010a). Wider recognition of the social model of disability has led to improved policy focusing on the disability rights and independent living agendas (Dean 2007). In recent times, there has been limited policy direction for disabled children also. Recognition of the particular vulnerability of this group led to Aiming High for Disabled Children Programme, providing funding of £429 m to develop and improve services for disabled children and their families between 2008 and 2011 (DfES 2007). However, campaigners criticise the lack of direction concerning services for disabled children, highlighting how coalition government spending reviews jeopardised both current and future services funded through Aiming High (EDCM 2010b).

The contemporary Strategy for Child Health (DH 2009) follows a familiar path, identifying generic health and education outcomes for healthy children and young people which may be unachievable for those with additional health needs (DH 2009). Furthermore, whilst the latter group of children is identified within the Strategy or Child Health, policy measures for this group emphasise service delivery outcomes rather than personal objectives (DH 2009). There has, however, been recent limited policy recognition of dying children as a distinct group.

Measurement of the scale of the issue (Cochrane et al. 2007) and a review of support services (Craft and Killen 2007) established government priorities for children's palliative care services developments (DH 2008). However, changes in government alter priorities. Moreover, the funding and sustainability of these services are dependent upon the voluntary sector (Craft and Killen 2007). This illustrates ambivalence in attitudes towards dying children and their parents. State and individuals increasingly focus upon protecting children and valuing them for their sentimental worth. However, the most vulnerable children have been largely ignored both in policy and practice. Meanwhile their parents, who face the loss of both the child and the values they fulfil, are unable to protect them or enable them to achieve state measures of well-being.

Societal ambivalence towards dying and disabled children is also clear. Parents are expected to grieve when their child experiences impairment (Runswick-Cole 2010). The notion that a disabled child's life is of less value than that of an able-bodied child persists. There is a historical perspective on disability suggesting that it is better to be dead than disabled

(Runswicke-Cole 2010). Thus, living with a disabled child may be perceived by observers as 'abnormal living' (Todd 2007, 642). Parental love for the child may not be externally validated (Milo 1997), and parents recognise that other people think their child would be better off dead (Runswicke-Cole 2010; Milo 1997). Moreover, opportunities to articulate the gains from parenting a disabled child may be limited (Black 2011; Todd 2007). However, the lack of value of the child's life is further underscored by reactions to their dying and death.

Parents may have difficulty finding safe spaces in which to articulate the reality of their child's impending death (Black 2011; Runswicke-Cole 2010). Acknowledging the possible death of another's child may raise intolerable concerns about one's own children (Todd 2007). Within disability studies, death is noted as an offensive presence with which researchers have difficulty engaging (Todd 2007; Runswicke-Cole 2010). When death does occur, however, there may be a 'socially imposed silence' (Todd 2007, 646). The loss of the child and the love felt for them may not be acknowledged or validated (Milo 1997). Indeed, the parental grief at the death of a disabled child may be delegitimated (Todd 2007).

Conclusions

The value of children has developed from economic benefit to parents and society towards recognition of psychological and sentimental outcomes fulfilled by children for parents (Zelizer 1994; Hoffman and Hoffman 1973). Children are nurtured by parents and state through a socially constructed and extended childhood which facilitates their development from 'human becomings' to human beings (Qvortrup 2005). However, ambivalence towards children persists, as they are alternately perceived as victim of or threat to society (Furlong and Cartmel 2007). In this respect, minority groups with respect to race or class may be particularly vulnerable to being overlooked or stigmatised by policy provision (Furlong and Cartmel 2007).

Dying children are one such minority group facing strong ambivalence. Costly investment in technologies to ensure the survival of premature infants and treatment of childhood disease is mismatched against a lack of attention to supporting the same children to live well with disability and ongoing ill health (Craft and Killen 2007). The value to society of dying children is questionable: their survival is not possible, and their 'human becoming' is compromised.

As long as social policy for children remains focused upon achievement of developmental norms, there is a risk that those whose development follows an alternative pathway, through disability or disease, will be overlooked and undervalued. Policy which standardises childhood within narrow boundaries therefore ensures that the nature of a dying child's 'being' also remains largely unaddressed. Disease and/or disability may prevent the attainment of norms which are privileged by society, whilst individual achievements may not be recognised and may be delegitimated. Therefore, the value of dying children to their parents is also unacknowledged (Todd 2007; Milo 1997; Runswicke-Cole 2010). Dying children remain among the most vulnerable in English society. However, their value to society, both in their living and their dying, remains largely unrecognised and all too often delegitimated (Todd 2007).

Short Biography

Rachel Black is the Nurse Consultant at Demelza Hospice Care for Children. She holds honorary positions at the University of Kent and Kings College London and previously worked as a lecturer at the University of Leeds. Her empirical research concerns the sociology of suffering and emotion management, particularly with respect to the lived experience of parents of dying children. She is currently working on studies about the role of emotion management in promoting resilience in healthcare and the use of visual methods to explore the concept of suffering amongst children and their families who use children's palliative care

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Note

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