Early childhood service delivery for families living with childhood disability: Disabling families through problematic implicit ideology

Lauren J. Breen
Edith Cowan University

THE AIM OF THIS PAPER is to unpack the implicit ideology underpinning early childhood service delivery for families living with childhood disability. The family as the unit of care is central to the philosophy and practice of early childhood services. However, the practice of family-centred care can be problematic; it is based upon neo-liberal assumptions of ‘idealised’ families, underestimates the profound impact of childhood disability on the family, and encourages service providers to conflate parents’ involvement in care with responsibility for it. Further, the notion of chronic sorrow is often applied in order to describe parents and/or families as either ‘in denial’ or too aggrieved to enact their therapeutic imperative, and individualised and psychologised interpretations are made. Service delivery in early childhood settings often reinforces—rather than acts to reduce—social, cultural and economic injustices. Clearly then, childhood disability remains institutionalised, but just within the institution of the family. Attention to the largely silenced, yet multiple, shifting, and complex issues faced by families living with childhood disability is required and will likely have implications for early childhood service delivery.

APPROXIMATELY 317,900, OR 8.3 per cent, of Australian children are classified as having a disability (Australian Institute of Health and Welfare [AIHW], 2006), and while impairment(s) vary greatly across a continuum, about half of all children with disability are described as having a ‘severe or profound core activity restriction’ (AIHW, 2004, p. xii). Almost all children with disability are cared for by their families within the family home. Although biomedical and economic explanations of disability remain paramount in some domains, increasingly the role of social, cultural, economic, environmental and political factors that act to ‘disable’ persons with impairment is emphasised within Australia and elsewhere (Goggin & Newell, 2005; Schalock, 2004; World Health Organization, 2001). Thus, while ‘impairments’ might restrict participation in activity, they are not necessarily the cause of disability. Disability activists within Australia prefer the term ‘person with disability’ (Goggin & Newell, 2005) but my use of this term is done with critical acknowledgement of the structural barriers that ultimately determine the health and wellbeing of families living with childhood disability.

In this paper I reflect upon the implicit ideology underlying early childhood service delivery for families living with childhood disability. I first consider the notion that the provision of care in the home by the family is ideal. Second, I discuss how parental involvement in professionalised care and therapy is often confused with the responsibility for it, especially for mothers. Third, I review the impact of childhood disability on the family, and in particular focus on the economic hardship, the potential for relationship difficulties with spouses and other children, restrictions in the ability to participate in leisure activities, loss of friendship networks, and the negotiation of complex and dense support services and systems of care. Fourth, I review the notion of chronic sorrow for families living with childhood disability and discuss the utility of the concept. Finally, I demonstrate that childhood disability services may replicate and exacerbate existing social, cultural and economic inequalities.

Assumption 1: Care in the home by the family is ideal

Welfare reform within Australia since the 1970s has shifted the responsibility for care from the state to the home. The policies and practices of de-institutionalisation and non-institutionalisation within Australia (and elsewhere), combined with neo-liberalist ideology which assumes that care in the home by the family is ideal, result in families’ self-care and self-help, and community services (Lennon, 2007; King & Scott, 2005; Lim, 2004; Anderson, 2000; Lyon, 1999). Care in the home and family support are the first line of care for children with disabilities. In 2002, Raghavan, Lyon, and Hurley stated, ‘The first line of care is making sure that care is available to the child and family member’ (Summerfield, 2002, p. 8). The results of this study suggest that King & Scott’s (2005) assumption that care in the home is ideal applies only to the families of children with minimal disabilities.
ideal (O’Connor, Orioff & Shaver, 1999; Peter, Spalding, Kenny, Conrad, McKeever & MacFarlane, 2007), has resulted in families undertaking the care of their children with disability, and this care is expected to be largely self-reliant, autonomous and unpaid. The notion of the traditional or nuclear family as ‘ideal’ providers of care pervades Australian welfare policy (Hill, 2007) and service delivery models of childhood health and disability services across Australia and elsewhere.

Paralleling this construction of an ‘ideal’ family is the problematic notion that families are functional, cohesive, supportive, able to meet the needs of all members, and capable of managing various predicaments. These assumptions permeate service provision for childhood disability (Dodds, Saggars & Wildy, 2009; Peter et al., 2007; Shogren & Turnbull, 2006). The family as the unit of care is central to the philosophy and practice of contemporary early childhood settings (Ashton et al., 2008), and is enacted through models of care such as family-centred care, which recognises the central role the family occupies in the life of a child (Shields, Pratt & Hunter, 2008) and acknowledges that the families are the ‘experts’ when it comes to recognising and meeting their child’s needs (Breen & Saggars, 2008; Raghavendra, Murchland, Bentley, Wake-Dyther & Lyons, 2007). A fundamental feature of family-centred care is the inclusion of the family in the decision-making processes concerning the child (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Corlett & Twycross 2006; King, Kartoy, King, Law, Rosenbaum & Hurley, 2003) and it is assumed that this collaboration results in optimal outcomes for the child (King, Teplicky, King & Rosenbaum, 2004; MacKean, Thurston & Scott, 2005; Shields et al, 2006). Consequently, the assumption concerning the ideal context of care leads to the next assumption concerning the responsibility for care, which is explored in the next section.

**Assumption 2: Parents (especially mothers) are responsible for care**

The application of family-centred care can be challenging. Significantly, there is a tendency for professionals to confuse parents’ involvement in care with responsibility for it. A recent Australian study demonstrated that allied health practitioners within childhood disability services regularly conflated parental involvement in the decision-making processes relating to the care of their child with responsibility for the provision of treatment (Dodds et al., 2009). Similarly, occupational therapists working with children with developmental disability in the United States revealed that they reported spending two-thirds of their time directing parents in the therapeutic care of their child (Hinojosa, Sproat, Mankhetiw & Anderson, 2002). A Canadian study revealed that parents of children with autism, Down syndrome, and developmental delays expressed feeling overwhelmed by the degree of responsibility for designing and implementing therapy expected of them by service providers (MacKean et al., 2005). Leiter (2004) termed this expectation that parents (usually mothers) will provide the therapy for their children as the ‘therapeutic imperative’ (p. 1371). It is perhaps unsurprising, then, that a recent review of several studies revealed that family-centred care often resulted in families caring for their children with disability with limited professional supports (Shields et al, 2006).

The transfer of caring responsibility to the family is complicated further by the gendered nature of care. An idealised family tends to consist of a heterosexual couple with a (usually male) breadwinner and a (usually female) carer of children (Saggars & Sime, 2006), and this pattern is typically reproduced within families faced with childhood disability (Gray, 2003; Lewis, Kagan & Heaton, 2000). Indeed, recent Australian figures on childhood disability establish that 85 percent of primary carers of children with disability are the children’s mothers, and nearly another five percent are women relatives and family friends (AIHW, 2004). Various studies demonstrate mothers of children with disability report being judged by service providers and employers (and themselves) for pursuing paid work outside the home and feel pressure from service providers to resign from paid employment in order to engage fully in the therapy regime (Gray, 2003; McKeen et al., 2005; Shearn & Todd, 2005).

The requirement of intensive motherhood (Caputo, 2007) necessitates self-sacrifice, and empirical research demonstrates that the health of mothers of children with disability is likely to be compromised. For example, one Australian study indicated that the self-reported health status of mothers of school-aged children with high support needs was significantly worse than that of mothers who did not have children with disability (McConnell & Llewellyn, 2006). A study of primary caregivers (mostly mothers) of two-year-old children in Canada at risk of developmental delay reported that 20 percent were clinically depressed, which was more than three times the community prevalence of depression for married mothers (Feldman, McDonald, Sorbin, Stack, Sacco & Yu, 2007). This assumption concerning the responsibility for care may underestimate the potentially profound impacts on families living with childhood disability, which is explored in the next section.

**Assumption 3: The transfer of care impacts minimally on the family system**

Childhood disability can profoundly affect the family or household unit. Notwithstanding the wide variation of impairments described as a childhood disability, it is generally recognised that families raising children with
disability bear a larger financial burden than do families with "typical" children. This includes the costs of goods and services such as continence products, additional heating, medication, and specialised equipment and transport (Murray, 2007). Studies in the United Kingdom and the United States demonstrate that the economic cost of raising a child with disability is significantly greater than raising a child without disability (Dobson & Middleton, 1996; Parish, Rose, Grinstein-Weiss, Richman & Andrews, 2008).

In Australia, formal financial support is available from the Commonwealth Government through a Carer Allowance, Carer Payment, and other types of assistance such as concession cards, rent assistance, and pharmaceutical subsidies (often described as 'benefits'). The eligibility criteria for Carer Allowance and Payment are strict—the majority of carers do not receive them—and parents caring for their children considered that the payments fail to recognise their considerable efforts (Murray, 2007). For example, when combined, the full Carer Payment and Allowance is still $200 less per week than the Australian minimum wage (Hughes, 2007). Sixty-one per cent of primary carers of children with disability report difficulties in meeting living expenses and 62 per cent rely on government allowances as their main source of income (AIHW, 2004).

Despite the limited financial support, paid work is often incompatible with the circumstances and complex needs of families living with childhood disability. More than half of all primary carers of 0- to 14-year-old children with disability report spending more than 40 hours a week engaged in care work (AIHW, 2004). In Australia, mothers of children with disability are significantly less likely to be in paid work than are other mothers, and, if they are employed, it is considerably more likely to be on a part-time basis (AIHW, 2004). Additionally, children with disability are twice as likely to live in one-parent households (usually headed by mothers) than are other children (AIHW, 2004), and this intensifies the financial strain. Studies of Welsh and American mothers of school-aged children with disability revealed that the time-intensive demands of care work, the lack of workplace flexibility, and the dearth of alternative and appropriate care left little room for paid work (Green, 2007; Litt, 2004; Shearn & Todd, 2000). Indeed, single mothers of children with disability in the United States are significantly more likely to remain dependent on welfare than are other mothers (Brandon & Hogan, 2004). The combined effect of increased costs relating to care and limited income leads to financial disadvantage, so it is perhaps unsurprising that childhood disability is associated substantially with poverty (AIHW, 2004).

In addition to the economic hardship, the potential for relationship difficulties is exacerbated for families living with childhood disability. The parental relationship is often affected because the different (gendered) and time-consuming roles of care (i.e., the mother engaging in the day-to-day care work and the father working long hours in paid employment to cover the costs of that care) leave the couple with little time to focus on that relationship (Gray, 2003; Green, 2007; Murray, 2007). Recent Australian figures reveal that 26 per cent of primary carers of children with disability described their marital/spousal relationship as strained and 20 per cent reported a lack of time to be together as a couple (AIHW, 2004). Additionally, siblings of children with disability often report feelings of loneliness, resentment and responsibility (Strohm, 2002).

Further, changes in social networks often follow the birth or diagnosis of a child with disability. Half of Australian parent-carers report either a change or end to their relationships with friends (AIHW, 2004). The parents in Murray's (2007) study reported that while some friendships continued, others did not. In other studies, Welsh mothers of school-aged children with intellectual disability reported difficulties in maintaining social contacts because of feeling different or marginalised from others (Shearn & Todd, 2000), while American mothers of children with disability reported several examples of feeling distressed by the reactions from other people (Fox, Vaughn, Wyatte & Dunlap, 2002; Green, 2007).

Families living with childhood disability also tend to experience significant restrictions in their ability to participate in leisure activities. The demands of care, which have been described as '24-hour, 7-day involvement' (Fox et al., 2002, p. 444) leave little time and money for families to engage in recreation activities, and this is further complicated by physical inaccessibility to recreation facilities and public toilets, intolerance and bigotry, and the child's persistent care needs (Murray, 2007). As such, the families in Murray's study rarely or never holidayed or ate out together. Importantly, even when families access respite services (Murray, 2007), or do attempt holidays (Mactavish, MacKay, Iwasski & Betteridge, 2007), their limited money and time, diminished social networks; and experiences of social stigma, combined with accessibility problems and ongoing care requirements, provided limited choice for leisure pursuits.

Families are also faced with negotiating the often complicated and confusing structured support services and systems of care for their children with disability. Community service supports are often inadequate, fractured, difficult to access, and under-resourced; they tend to compete rather than collaborate with one another, and are beleaguered with issues of staff inexperience.

In one study, one in three families reported actually having a bad experience while seeking support (Milo, 2003). This is not unexpected. The problems experienced by families in the provision of support services mirror those experienced by children with disability. One study found that 60 per cent of families were unable to find support services, or the service was not what they expected (MacKean, 2000, exp. 2004; Green, 2007; Shearn & Todd, 2000). One study found that 60 per cent of families of children under 15 years of age in the United States or 'normal' children are at a higher risk than families with children who have a disability (Milo, 2003).

Parents of children with a disability often experience grief without the benefit and support that may be available to a loss of a loved one.
inexperience and attrition (McDonald & Zetlin, 2004). In one study, the negotiation of numerous services and stakeholders was described by one mother as 'a bit like running a small business' (Kingdom & Mayfield, 2001, p. 38) while parents in other studies conducted in Canada, the United States and the United Kingdom reported 'fighting' for resources and feeling frustrated and fatigued (Darrah, Magli-Evans & Adams, 2002; Green, 2007; Litt, 2004; MacKean et al., 2005; Swain & Walker, 2003). As a result, some parents/families attempt to advocate for additional resources such as accessible local parks, increased access to transport and specially equipped, and the establishment of a mutual help group (Murray, 2007). However, such attempts are limited by the diminished time and resources available (Darrah et al., 2002; Litt, 2004) and may also be constrained by their internalisation of their exclusion (Goggin & Newell, 2005).

Assumption 4: Parents may experience grief as a result of the ‘tragedy’

It is important to state the positive outcomes of having a child or sibling with disability, and these include empathy, joy, optimism, courage, resourcefulness, tolerance, and a heightened appreciation for life (Green, 2007; Kearney & Griffin, 2001; True, Hiebert-Murphy & Levine, 2007). At the same time, however, parents and siblings of children with disability do report feelings of sadness, loss, and grief. While most of the theories and empirical research studies of grief are based upon bereavement through physical death (Center for the Advancement of Health, 2004), it is generally recognised that any loss may precipitate a grief response. For a family, childhood disability encompasses many losses, some tangible and some intangible. Parents might worry about the long-term care of their children (Murray, 2007), tend to lose their independence and/or careers (Gray, 2003; MacKean et al., 2005; Murray, 2007; Shearn & Todd, 2000, experience significant financial stressors (AHW, 2004; Green, 2007; Litt, 2004; Murray, 2007; Shearn & Todd, 2000), and report a shattered sense of normalcy, hopes, dreams, and the 'metaphorical death' of the expected healthy child (Wood & Milo, 2001, p. 644).

One study reported that the initial grief following the loss of the child lasted an average of five years (Green, 2007). Parallel to these losses, siblings of children with disability often report the loss of a normal childhood (Strohm, 2002). Of course, given the higher risk of death for children with disability, some families report experiencing the ‘double loss’ (Wood & Milo, 2001, p. 643) of the death of their child.

Parents of a child with disability may also reveal their grief when talking about their experiences (Gray, 2003; Murray, 2007) and often the grief process is referred to as a long-term phenomenon. In one study, a mother
Assumption 5: Service delivery reduces social, cultural and economic injustices

Childhood disability services tend to reinforce and exacerbate existing social, cultural, and economic injustices. First, gender disadvantage is often exaggerated by the requirement of intensive maternal care (Caputo, 2007) which shifts the costs and responsibilities of care to parents (usually mothers) (King et al., 2003; Leiter, 2004; MacKean et al., 2005). For example, one Australian study of mothers and fathers of children with disability reported that time for personal care and leisure was reduced for mothers while fathers remained unaffected (Brandon, 2007).

Additionally, a Canadian study revealed that the self-reported health of mothers of children with disability was affected more negatively than was their husband’s health, particularly over longer periods (Burton, Leithbridge & Phipps, 2008).

Second, ethnic and cultural disadvantage is often exacerbated. There is little research on childhood disability in families of culturally and linguistically diverse backgrounds, despite its obvious importance to service provision in Australia and elsewhere. However, concepts of care might not translate cross-culturally (Goldbart & Mukherjee, 1998; Harrison & Kehn, 2004; Harry, 2008), and parents with no or limited English competency are often excluded from studies because measures are not translated. Further, the perception by service providers of disability as ‘deficit’ may be exacerbated in families from non-dominant ethnic and cultural backgrounds (Harry, 2008).

A study of Pakistani and Bangladeshi parents of children with disability in the United Kingdom demonstrated that their immense difficulties in accessing services was a result of discrimination and institutionalised racism (Fazel, Bywaters, Alil, Wallace & Singh, 2002).

Third, financial disadvantage may be exacerbated. Childhood disability is almost inexorably linked with poverty (AIHW, 2004; Brandon & Hogan, 2004; Litl, 2004; Murray, 2007), which in turn impacts significantly on each family’s stress, nutrition, home sanitation, access to health care, opportunities for leisure, and overall quality of life, which then has a negative influence on child development (Park, Turnbull & Turnbull, 2002).

If families are financially-advantaged the mother might forgo paid work to be more readily able to fulfil the roles and responsibilities expected of them by service providers than are families with fewer social and economic resources. Additionally, low-income families differ greatly from privileged families in terms of their ability to afford services, negotiate bureaucracies, advocate for resources, and access and maintain flexible and well-paid employment, and these factors combine to influence their financial status over the long term (Brandon & Hogan, 2004; Litl, 2004).

Of course, it is very common for several of these forms of disadvantage to occur simultaneously (Dowling & Dolan, 2001), reinforcing the ‘trauma’ discourse of childhood disability. Indeed, some authors have argued that disadvantage goes beyond the individual child. For example, Fazi et al. (2002) asserted, ‘it is the family as a whole that is disabled by the unjust society’ (p. 238), while Brett (2002) referred to the impact of the injustices on the family as ‘disability proxy’ (p. 832).

Families in crisis or hardship usually believe that structured service settings will assist them, but this is not often the case. By no means am I criticising individual service providers and therapists. However, what they are able to achieve is severely restricted by the application of economic rationalism and market models to their work, which has led to reductions in organisational stability, increased competition rather than cooperation between services, high staff turnover, and reduced funding (Green, Green, Roarty & Seggers, 2008). Given the very real hardships and social isolation encountered by families living with childhood disability, their ‘fight’ for assistance and resources, their negotiation of dense and confusing service systems, and the transfer of therapy roles to families (particularly mothers), the social, economic, and systemic injustices in and of themselves are likely to be, at the very least, a fundamental component of any sorrow or grief experienced by such families. It is these factors, and not the ‘trauma of disability’ that are likely to be the cause of any ‘sorrow’.

Conclusion

This commentary has highlighted several assumptions that have been challenged but continue to pervade childhood services: The assumption of ‘idealised families’, the assumption that parents, especially mothers, involvement in care equates to responsibilities for it, the assumption that the intense involvement does not impact greatly on the family system, the assumption that parents and/or families might experience grief responses, and the assumption that intervention reduces social, cultural, and economic inequalities. These neo-liberal and individualised and economic rationalist notions are powerful and have the potential to conceal both the lived experiences of families living with childhood disability beyond the discourse of individual or familial ‘trajectory’.

The everyday experience of families living with childhood disability and faced with negotiating the complexities of care do not easily correspond with the discourses of service delivery. It is clear that the implicit ideology and practices of early childhood service delivery has the potential to reinforce, rather than reduce, social, cultural, and economic injustices. Clearly, then, childhood disability remains institutionalised, but just within the institutions of the family, rendering

the family powerless by families. Critically unequipped, early childhood services require urgent change. Responsibility for services and institutional change occurs within systems that are unthinking and not faced by families required and the concerns of early childhood professionals.

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The author can be contacted:
Dr Lauren J. Brandon
Social Justice and Disability
School of Psychology
Edith Cowan University
270 Joondalup Drive
JOONDALUP
Western Australia
Email:ibre@ecu.edu.au

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the family as ‘disabled’. The complex issues faced by families coloured by childhood disability remains critically under-explored and under-developed within early childhood research and practice. These issues require urgent attention given the increased roles and responsibilities expected of families as a result of non-institutionalisation and the expectation that care ‘best’ occurs within the home and by the family. However, thought and comprehensive attention to the largely silenced, yet multiple, shifting, and complex injustices faced by families living with childhood disability is required and will likely have significant implications for early childhood service delivery.

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The author can be contacted at:

Dr Lauren J. Breen
Social Justice Research Centre
School of Psychology and Social Science
Edith Cowan University
270 Joondalup Drive
JOONDALUP 6027
Western Australia
Email: l.breen@ecu.edu.au

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