

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

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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 (O'Connor, Orloff & 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 (Dodd, Siggers & 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, 2006) and acknowledges that the families are the 'experts' when it comes to recognising and meeting their child's needs (Breen & Siggers, 2009; Raghavendra, Murchland, Bentley, Wake-Dyster & 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, Kertoy, 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 (Dodd 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, Mankhetwit & 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. 837). 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 (Siggers & Sims, 2005), 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 per cent of primary carers of children with disability are the children's mothers, and nearly another five per cent 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 felt pressure from service providers to resign from paid employment in order to engage fully in the therapy regime (Gray, 2003; MacKean et al., 2005; Shearn & Todd, 2000).

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 per cent were clinically depressed, which was more than three times the community prevalence of depression for married mothers (Feldman, McDonald, Serbin, Stack, Secco & 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, 1998; 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 appropriate alternative 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 in 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 addition, the parents cited the limited time they had to cultivate existing or new friendships. 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, Wyatt & 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, Iwasaki & 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 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, Magil-Evans & Adkins, 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 specialised equipment, 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; Trute, 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 child(ren) (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 (AIHW, 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 imagined 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 children 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

of a child with disability referred to her experiences as characterised by 'constant grief' (Gray, 2003, p. 636), while Strohm (2002) dedicated a chapter to a discussion of 'ongoing grief'. The notion of chronic sorrow was proposed more than four decades ago to describe the experiences of recurrent losses over the long term brought about by raising a child with disability (Olshansky, 1962). The concept of chronic sorrow has since been developed further, particularly in the nursing literature (e.g. Lindgren, Burke, Hainsworth & Eakes, 1992), and has been embraced by nurses and many health professionals working with families living with childhood disability (Ferguson, Gartner & Lipsky, 2000; Foley, 2006; Landsman, 2003; Perryman, 2005).

However, the notion of chronic sorrow or grief and its application to families living with chronic disability is largely problematic. It borrows from medicalised and psychologised discourses which construct the 'deficit' on the part of the individual or family while the social environments remain unchallenged and unchanged (Oliver, 1983; Prilleltensky & Nelson, 2000). For example, it has been argued by several researchers and commentators that parental experiences of chronic sorrow should be 'normalised' by empathetic health professionals and 'treated' by the fostering of appropriate cognitive, affective and behavioural coping skills (Barlow, Swaby & Turner, 2008; Barnett, Clements, Kaplan-Estrin & Fialka, 2003; Eakes, Burke & Hainsworth, 1998; Hobdell, 2004). I argue that the notion of chronic grief or sorrow draws upon a 'disability as tragedy' discourse and therefore may be applied in order to describe parents and/or families as either 'denying' their grief or being unable to 'accept' their reality of caring for a child or children with disability (Ferguson, 2001; Ferguson et al., 2000; Hobdell et al., 2007; Kearney & Griffin, 2001; McKeever & Miller, 2004), with little or no attention to the social, cultural and economic milieu. In an analysis of grief and coping following diagnosis of hearing loss in a child, Kurtzer-White and Luterman (2003) stated, 'It appears that we have not put in place the necessary management programs to complement the screening program and the majority of parents are being left on their own to cope with the myriad of feelings engendered by the diagnosis' (p. 235). Similarly, Green (2007) asserted, 'The majority of research on caring for children with disabilities has emphasised the emotional distress of having a child with a disability and de-emphasised both the benefits of caring and the negative consequences of stigma and socio-structural constraints' (p. 161). Thus, the underlying aim of the construct of chronic sorrow, and the resulting 'treatments' (where offered), is to ensure that that families (especially mothers) better enact their therapeutic imperative without increased assistance from the state.

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 motherhood (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, Lethbridge & 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, 1999; Harrison & Kahn, 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 (Fazil, Bywaters, Ali, Wallace & Singh, 2002).

Third, financial disadvantage may be exacerbated. Childhood disability is almost inexorably linked with poverty (AIHW, 2004; Brandon & Hogan, 2004; Litt, 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). The financially-advantaged family wherein the mother can forgo paid work is likely 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; Litt, 2004).

Of course, it is very common for several of these forms of disadvantage to occur simultaneously (Dowling & Dolan, 2001), reinforcing the 'tragedy' discourse of childhood disability. Indeed, some authors have argued that disablement goes beyond the individual child. For example, Fazil 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 'disablement by 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 (Breen, Green, Roarty & Saggars, 2008). Given the economic 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 'tragedy 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 responsibility for it, the assumption that the intensive 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, individualised and economic rationalist notions are powerful and have the potential to conceal the daily lived experiences of families living with childhood disability behind the discourse of individual or familial 'tragedy'.

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 institution of the family, rendering

the family as 'disabled'. The complex issues faced by families coloured by childhood disability remains critically under-explored and underdeveloped 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, thoughtful 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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References

- Ashton, J., Woodrow, C., Johnson, C., Wangmann, J., Singh, L., & James, T. (2008). Partnerships in learning: Linking early childhood services, families and schools for optimal development. *Australian Journal of Early Childhood, 33*(2), 10-16.
- Australian Institute of Health and Welfare (2004). *Children with disabilities in Australia*. AIHW Cat. No. DIS38. Canberra, Australia: Author.
- Australian Institute of Health and Welfare (2006). *Disability updates: Children with disabilities*. Bulletin No. 42. AIHW Cat. No. AUS19. Canberra, Australia: Author.
- Barlow, J., Swaby, L., & Turner, A. (2008). Perspectives of parents and tutors on a self-management program for parents/guardians of children with long-term and life-limiting conditions: 'A life raft we can sail along with'. *Journal of Community Psychology, 36*, 871-884.
- Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: Supporting parents' adaptation to their child with special needs. *Infants and Young Children, 16*, 184-200.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children, 70*, 167- 184.
- Brandon, P. (2007). Time away from "smelling the roses": Where do mothers raising children with disabilities find the time to work? *Social Science and Medicine, 65*, 667-679.
- Brandon, P. D., & Hogan, D. P. (2004). Impediments to mothers leaving welfare: The role of maternal and child disability. *Population Research and Policy Review, 23*, 419-436.
- Breen, L. J., Green, M. J., Roarty, L., & Saggars, S. (2008). Towards embedding wellness approaches to health and disability in the policies and practices of allied health providers. *Journal of Allied Health, 37*, 173-179.
- Breen, L. J., & Saggars, S. (2009). Wellness rhetoric: Implications for policy and practice in Australian childhood health and disability services. In C. A. Marshall, E. Kendall, M. E. Banks, & R. M. S. Gover (Eds.), *Disabilities: Insights from across fields and around the world* (Vol. 3, pp. 167-179). Westport, CT: Praeger.
- Brett, J. (2002). The experience of disability from the perspectives of parents of children with profound impairment: Is it time for an alternative model of disability? *Disability and Society, 17*, 825-843.
- Burton, P., Lethbridge, L., & Phipps, S. (2008). Children with disabilities and chronic conditions and longer-term parental health. *The Journal of Socio-Economics, 37*, 1168-1186.
- Caputo, V. (2007). She's from a 'good family': Performing childhood and motherhood in a Canadian private school setting. *Childhood, 14*, 173-192.
- Center for the Advancement of Health. (2004). Report on bereavement and grief research. *Death Studies, 28*, 491-575.
- Corlett, J., & Twycross, A. (2006). Negotiation of parent role within family-centred care: A review of the research. *Journal of Clinical Nursing, 15*, 1308-1316.
- Darrah, J., Magil-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation, 24*, 542-549.
- Dobson, B., & Middleton, S. (1998). *The cost of childhood disability*. Joseph Rowntree Foundation. Accessed 3 March 2008 from: <http://www.jrf.org.uk/knowledge/findings/socialcare/SCR748.asp>
- Dodd, J., Saggars, S. & Wildy, H. (2009). Constructing the ideal family for family centred practice: Challenges for delivery. *Disability and Society, 24*, 173-186.
- Dowling, M., & Dolan, L. (2001). Families with children with disabilities: Inequalities and the social model. *Disability and Society, 16*, 21-35.
- Eakes, G. G., Burke, M. L., & Hainsworth, M. A. (1998). Middle-range theory of chronic sorrow. *Image: The Journal of Nursing Scholarship, 30*, 179-184.
- Fazil, Q., Bywaters, P., Ali, Z., Wallace, L., & Singh, G. (2002). Disadvantage and discrimination compounded: The experience of Pakistani and Bangladeshi parents of disabled children in the UK. *Disability and Society, 17*, 237-253.
- Feldman, M., McDonald, L., Serbin, L., Stack, D., Secco, M. L., & Yu, C. T. (2007). Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *Journal of Intellectual Disability Research, 51*, 606-619.
- Ferguson, P. M. (2001). Mapping the family: Disability studies and the exploration of parental response to disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds), *Handbook of disability studies* (pp. 373-395). Thousand Oaks, CA: Sage.
- Ferguson, P. M., Gartner, A., & Lipsky, D. K. (2000). The experience of disability in families: A synthesis of research and parent narratives. In E. Parens & A. Asch (2000). *Prenatal testing and disability rights* (pp. 72-94). Washington, DC: Georgetown University Press.

- Foley, G. M. (2006). The loss-grief cycle: Coming to terms with the birth of a child with a disability. In G. M. Foley & J. Hochman (Eds.), *Mental health in early intervention: Achieving unity in principles and practice* (pp. 227-243). Baltimore, MD: Paul H. Brookes.
- Fox, L., Vaughn, B. J., Wyatte, M. L., & Dunlap, G. (2002). "We can't expect other people to understand": Family perspectives on problem behavior. *Exceptional Children, 68*, 437-450.
- Goggin, G., & Newell, C. (2005). *Disability in Australia: Exposing a social apartheid*. Sydney, University of New South Wales Press.
- Goldbart, J., & Mukherjee, S. (1999). The appropriateness of Western models of parent involvement in Calcutta, India. Part 2: Implications of family roles and responsibilities. *Child: Care, Health and Development, 25*, 348-358.
- Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine, 56*, 631-642.
- Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine, 64*, 150-163.
- Harrison, T. C., & Kahn, D. L. (2004). Disability rites: The cultural shift following impairment. *Family and Community Health, 2004*, 86-93.
- Harry, B. (2008). Collaboration with culturally and linguistically diverse families: Ideal versus reality. *Exceptional Children, 74*, 372-388.
- Hill, S. (2007). Budgeting for work-life balance: The ideology and politics of work and family policy in Australia. *Australian Bulletin of Labour, 33*, 226-245.
- Hinojosa, J., Sproat, C. T., Mankhetwit, S., & Anderson, J. (2002). Shifts in parent-therapist partnerships: Twelve years of change. *American Journal of Occupational Therapy, 56*, 556-563.
- Hobdell, E. (2004). Chronic sorrow and depression in parents of children with neural tube defects. *Journal of Neuroscience Nursing, 36*, 82-94.
- Hobdell, E. F., Grant, M. L., Valencia, I., Mare, J., Kothare, S. V., Legido, A., & Khurana, D. S. (2007). Chronic sorrow and coping in families of children with epilepsy. *Journal of Neuroscience Nursing, 39*, 76-82.
- Hughes, J. (2007). Caring for carers: The financial strain of caring. *Family Matters, 76*, 32-33.
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34*, 582-592.
- King, G., Kertoy, M., King, S., Law, M., Rosenbaum, P., & Hurley, P. (2003). A measure of parents' and service providers' beliefs about participation in family-centered services. *Children's Health Care, 32*, 191-214.
- King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centred service for children with cerebral palsy and their families: A review of the literature. *Seminars in Pediatric Neurology, 11*, 78-86.
- Kingdom, S., & Mayfield, C. (2001). Complex disabilities: Parents preparing professionals. *Paediatric Nursing, 13*(7), 34-38.
- Kurtzer-White, E., & Luterman, D. (2003). Families and children with hearing loss: Grief and coping. *Mental Retardation and Developmental Disabilities Research Reviews, 9*, 232-235.
- Landsman, G. (2003). Emplotting children's lives: Developmental delay vs. disability. *Social Science and Medicine, 56*, 1947-1960.
- Leiter, V. (2004). Dilemmas in sharing care: Maternal provision of professionally driven therapy for children with disabilities. *Social Science and Medicine, 58*, 837-849.
- Lewis, S., Kagan, C., & Heaton, P. (2000). Dual-earner parents with disabled children: Family patterns for working and caring. *Journal of Family Issues, 21*, 1031-1060.
- Lindgren, C. L., Burke, M. L., Hainsworth, M. A., & Eakes, G. G. (1992). Chronic sorrow: A lifespan concept. *Scholarly Inquiry for Nursing Practice, 6*, 27-40.
- Litt, J. (2004). Women's carework in low-income households: The special case of children with attention deficit hyperactivity disorder. *Gender and Society, 18*, 625-644.
- MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspective in family-centred care. *Health Expectations, 8*, 74-86.
- Mactavish, J. B., MacKay, K. J., Iwasaki, Y., & Betteridge, D. (2007). Family caregivers of individuals with intellectual disability: Perspectives of life quality and the role of vacations. *Journal of Leisure Research, 39*, 127-155.
- McConnell, D. & Llewellyn, G. (2006). Health of mothers of school-age children with disabilities. *Australian and New Zealand Journal of Public Health, 30*, 572-574.
- McDonald, C., & Zetlin, D. (2004). The promotion and disruption of community service delivery systems. *Australian Journal of Social Issues, 39*, 267-282.
- McKeever, P., & Miller, K. L. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science and Medicine, 59*, 1177-1191.
- Murray, S. (2007). Families' care of their children with severe disabilities in Australia. *Community, Work and Family, 10*, 215-230.
- O'Connor, J. S., Orloff, A. S., & Shaver, S. (1999). *States, markets, families: Gender, liberalism and social policy in Australia, Canada, Great Britain and the United States*. Cambridge. Cambridge University Press.
- Oliver M. (1983). *Social work with disabled people*. London: MacMillan.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43*, 191-193.
- Park, J., Turnbull, A. P., & Turnbull, H. R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children, 68*, 151-170.
- Parish, S. L., Rose, R. A., Grinstein-Weiss, M., Richman, E. L., & Andrews, M. E. (2008). Material hardship in U.S. families raising children with disabilities. *Exceptional Children, 75*, 71-92.
- Perryman, H. P. (2005). Parental reaction to the disabled child: Implications for family courts. *Family Court Review, 43*, 596-606.
- Peter, E., Spalding, K., Kenny, N., Conrad, P., McKeever, P., & Macfarlane, A. (2007). Neither seen nor heard: Children and homework policy in Canada. *Social Science and Medicine, 64*, 1624-1635.
- Prilleltensky, I., & Nelson, G. (2000). Promoting child and family wellness: Priorities for psychological and social interventions. *Journal of Community and Applied Social Psychology, 19*, 85-105.

Raghavendra, P., Murchland, S., Bentley, M., Wake-Dyster, W., & Lyons, T. (2007). Parents' and service providers' perceptions of family-centred practice in a community-based, paediatric disability service in Australia. *Child: Care, Health and Development*, 35, 586-592.

Saggers, S., & Sims, M. (2005). Diversity: Beyond the nuclear family. In M. Poole (Ed.), *Family: Changing families, changing times* (pp. 66-87). Sydney: Allen & Unwin.

Schalock, R. L. (2004). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies*, 14, 204-215.

Shearn, J., & Todd, S. (2000). Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 13, 109-131.

Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: A review of qualitative studies. *Journal of Clinical Nursing*, 15, 1317-1323.

Shogren, K. A., & Turnbull, A. P. (2006). Promoting self-determination in young children with disabilities. *Infants and Young Children*, 19, 338-352.

Strohm, K. (2002). *Siblings: Brothers and sisters of children with special needs*. Kent Town, South Australia: Wakefield Press.

Swain, J., & Walker, C. (2003). Parent-professional power relations: Parents and professional perspectives. *Disability and Society*, 18, 547-560.

Trute, B., Hiebert-Murphy, D., & Levine, K. (2007). Parental appraisal of the family impact of childhood development disability: Times of sadness and times of joy. *Journal of Intellectual and Developmental Disability*, 32, 1-9.

Wood, J. D., & Milo, E. (2001). Father's grief when a disabled child dies. *Death Studies*, 25, 635-661.

World Health Organization (2001). International classification of functioning, disability and health. Geneva: Author. Accessed March 14 2008 from: www.who.int/classifications/icf/en/

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Your one-stop guide to early childhood links and resources

Welcome to the first Autumn issue of *ECA WebWatch* for 2009. As the cold weather creeps closer, we are focusing on the call for ABC to remove *Bringing up Baby* from television.

Also in this issue:

- Book now—Conferences with Professor Iram Siraj-Blatchford
- UNICEF releases *State of the world's children* report
- Speeches by Maxine McKew
- New York's 'education revolution' and how it relates to Australia
- Helping children with Autism Spectrum Disorder

Plus:

- ECA calendar
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ECA WebWatch Feature Item

Call for ABC to cancel *Bringing up Baby*

ECA supports call to cancel *Bringing up Baby*

The ABC is currently screening a UK documentary series, *Bringing up Baby*, based on the guiding principles of three of last century's influential childcare manuals. The series has come under fire from lawyers, parents and experts for a range of reasons – in particular, the person promoting the Thuby King method. This method has been rejected by experts as dangerous and does not reflect the evidence on what's good for young children. This also raises significant ethical questions about using children in such programs.

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