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Responses: Practice, Legal, and Political Frameworks

Edited by

Catherine A. Marshall, Elizabeth Kendall, Martha E. Banks, and Reva Mariah S. Gover

Foreword by Thomas Bornemann

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Wellness Rhetoric: Implications for Policy and Practice in Australian Childhood Health and Disability Services

Lauren J. Breen and Sherry Saggers

Wellness approaches to service provision emerged from the social model of disability and are increasingly preferred throughout the health and disability service sectors worldwide. However, research continues to demonstrate that many health services and individual practitioners continue to operate according to medical models of illness. The aim of this chapter is to explore the rhetoric of wellness approaches to health and disability. As the first step toward embedding wellness approaches within childhood health and disability policy and practice, we investigated the policy and procedure documents of major childhood health and disability services across Australia. We conclude with some suggestions for how wellness approaches might be incorporated into policy and practices of childhood health and disability services.

Approximately four million Australians, or 20 percent of the country's population, are classified as having a disability, and this includes 317,900, or 8.3 percent, of the nation's children (Australian Institute of Health and Welfare, 2006). Childhood disability often has a profound effect on the family or household unit, especially in relation to the responsibility for care of a child with a disability (particularly by mothers): the negotiation of the often complicated and confusing structured support services and systems of care; the potential for relationship difficulties with other children and spouses, restrictions in the ability to participate in leisure activities, and loss of friendship networks; and economic hardship (Australian Institute of Health and Welfare, 2006; Dodd, Saggers, & Wildy, 2007; Murray, 2007; Trute, Hiebert-Murphy, & Levine, 2007).

Although the definitions of disability remain contested within Australia (Bowles, 2001), we define disability in accordance with the notion that a

person with impairment is "disabled" through social and environmental barriers (see Thoreau, 2006, pp. 446–447, or Barnes & Mercer, 2006, pp. 5–6, for discussions of terminology and its implications). However, while the social-political conceptualization appears to be the leading influence on social policy in Australia, the medical and economic paradigms are equally dominant when it comes to practice (Bowles, 2001). Despite the medical and economic dominance, wellness approaches, which emphasize health and well-being, are increasingly preferred for the delivery of health and disability services across Australia and internationally (Breen, Green, Roarty, & Saggers, in press).

THE SHIFT TO WELLNESS

Wellness is generally defined as a multifaceted and holistic understanding of health (e.g., Breen et al., in press; Jones & Kilpatrick, 1996; Kahn & Juster, 2002; Larson, 1999) and aligns with the social model of disability (Oliver, 1983) and the World Health Organization's (1948) enduring definition of health as "a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity" (p. 2). Throughout Australia, there are increasing demands by individuals and families for the delivery of health and disability services that empower and attend to issues of client wellbeing, independence, self-determination, and rights to meaningful and productive lives (Breen et al., in press). Further, principles of wellness approaches to health and disability also align with and are embedded within various national health strategies and policies as well as in similar state initiatives, which argue for resources to be directed to public health approaches that improve quality of life rather than acute care interventions.

Despite the paradigm shift toward wellness in Australian health services, the presence of theoretical, empirical, social, and political demands toward wellness (Breen et al., in press) and the recognition of and support for wellness within allied health disciplines, these remain misaligned with the practices in the health and disability sectors (Bowles, 2001; Goodgold, 2005; Hanna & Rodger, 2002; Saggers et al., 2002; Schalock, 2004; Wearing, 1999). Although many childhood health and disability services within Australia are committed to embedding wellness approaches into the practice of allied health service delivery, they face the challenge of implementing such approaches where the medical and economic models remain the powerful drivers of practice.

TOWARD EMBEDDING WELLNESS APPROACHES IN POLICY AND PRACTICE

A fundamental strategy for achieving health and wellness is the translation of research into policy and practice (Krahn, Putnam, Drum, & Powers, 2006). The incorporation of wellness approaches into childhood health and disability services requires holistic and complex changes to allied health professional education and training, practice, funding, and research (Breen et al., in press). Herein, we are concerned with the examination of policy and

procedure documents of major childhood disability services providing allied health services within Australia. Our aim was to determine how wellness is positioned rhetorically within key documents of selected childhood health and disability providers across Australia.

Using a multiple case study approach and content analysis, we describe how and where the indicators of wellness appear in the documents of major child-hood health and disability providers. The key indicators of wellness, as identified in Breen et al. (in press) guided the study. A multiple case study approach was employed because it is systematic, contextual, and utilizes multiple sources of data (Burgess-Limerick & Burgess-Limerick, 1998; Robson, 2002).

Through state government health Web sites, we identified all organizations and services providing any type of health or disability service to children (0 to 18 years) within three Australian states (Queensland, South Australia, and Western Australia). These lists were then reviewed by childhood allied health service providers and stakeholders within the states who provided details of relevant additional services. This process resulted in 10 services—three in Queensland, three in South Australia, and four in Western Australia. These organizations employed a range of allied health professionals, primarily occupational therapists, physiotherapists, speech pathologists, psychologists, and social workers. The services provided allied health services to children (0 to 18 years) either for specific impairment (i.e., vision; n = 1) or multiple impairments (n = 9), and included both government (n = 5) or not-for-profit nongovernment agencies (n = 5).

An initial perusal of the services' Web sites and consultation with allied health professionals in the childhood health and disability sector indicated that the policies and procedure documents requiring examination would include Web pages, annual reports, and strategic plans. Where annual reports or strategic plans were not available on the sites, the services were contacted and access to copies of these documents was requested.

To recognize a wellness approach within these policy and procedure documents, we searched for the presence of six key indicators of wellness approaches as identified in a review of the literature (Breen et al., in press) and via a process of consultation with allied health professionals employed in selected childhood health and disability services across Australia. The six key indicators were:

- shared control between client and practitioner;
- holistic definitions of health;
- individualized support, therapy, and intervention;
- the use of multidisciplinary teams;
- the provision of support from community-based settings; and
- advocacy/the politicization of health.

A matrix, consisting of a table where the columns represented the indicators of wellness and the rows represented the services, was constructed to record the presence (and therefore the absence) of evidence demonstrating each of the six key indicators of wellness. The construction of the data matrix was advantageous because it facilitated the systematic and logical reduction

and display of the data (Miles & Huberman, 1994). The Web sites, annual reports, and strategic plans for each organization were searched and excerpts that reflected each of the six key indicators were transposed into the matrix. In addition to the manual search, keywords (e.g., multidisciplinary, advocacy, wellness, decision making) within the six indicators were searched for using each Web site's search facility.

Once the matrix was constructed, a content analysis was performed on the data (Miles & Huberman, 1994; Robson, 2002). As well as facilitating the identification of wellness correlates within each organization, the matrix also facilitated the identification of patterns, themes, and contradictions that emerged *across* the organizations (Miles & Huberman, 1994). The analysis process resulted in a description of how and where the correlates of wellness appear in the documents and Web sites of the major Australian childhood health and disability providers.

THE RHETORIC OF WELLNESS

An overview of each of the 10 selected childhood health and disability services, and the presence of wellness indicators within them, is presented in Table 12.1. The number of wellness indicators identified in the Web site pages, annual reports, and strategic plans of each service ranged from just two to all six. The most common were:

- holistic definitions of health (n = 9);
- use of multidisciplinary teams (n = 9);
- provision of support from a community-based setting (n = 8)
- shared control between client and practitioner (n = 6);
- presence of individualized support, therapy, and intervention (n = 5); and
- advocacy/the politicization of health (n = 5).

Overall, the Web site pages, annual reports, and strategic plans of the nongovernment services were more likely than government documents to include more of the key indicators of wellness.

Each of the key indicators is presented next, with examples demonstrating how each was embedded within the Web site pages, annual reports, and strategic plans of the selected childhood health and disability services within Australia. All services are represented by their code number (see Table 12.1) and all names have been changed.

Holistic Definitions of Health

This indicator was evident in the use of phrases concerning the promotion of health. For example, the services aimed to promote "life-long health" (Service 1), aimed to "improve and promote their health and well-being" (Service 9), and stated that their mission is to "promote, maintain, and restore the health of women, children, and young people" (Service 5). Some stated that they assisted the children to "get the most out of life" (Service 3), promoted

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Table 1.	Table 12.1 Presence of Key Indicators of Wellness in Selected Childhood Health and Disability Services in Australia	Ith and Disability Services in Australia
Code	Description of Service	Presence of Wellness Indicators
	A state-wide, government-funded children's hospital.	Holistic definition of health; community-based; advocacy/the politicization of health.
7	A state-wide, government-funded service for children (primarily preschool age) with developmental and behavioral concerns.	Multidisciplinary teams; community-based; shared control.
m	A nongovernment service for children with physical, communication, and sensory impairments living in the main city of the state.	Shared control; holistic definition of health; individualized support; multidisciplinary teams; community-based; advocacy/the politicization of health.
4	A state-wide, nongovernment service for people with vision impairment; includes a children's service team specifically to meet the needs of children who are blind or vision impaired.	Shared control; holistic definition of health; individualized support; multidisciplinary teams; community-based; advocacy/the politicization of health.
rc 0	A state-wide, government-funded children's hospital. A state-wide, nongovernment service for children with physical	Holistic definition of health; multidisciplinary teams. Shared control; holistic definition of health; individualized
	and other impairments.	support; multidisciplinary teams; community-based; advocacy/the politicization of health.
1	A state-wide, nongovernment service for children with vision and/or hearing impairments or communication disorders.	Shared control; holistic definition of health; individualized support; multidisciplinary teams; community-based; advocacy/the politicization of health.
∞	A state-wide, government-funded children's hospital across the state and neighboring areas.	Holistic definition of health; multidisciplinary teams; community-based.
6	A state-wide, government-funded service for children with developmental and behavioral concerns.	Holistic definition of health; multidisciplinary teams.
10	A state-wide, nongovernment service for children with various	Shared control; holistic definition of health; individualized support;

multidisciplinary teams; community-based.

physical impairments.

"success in education and all aspects of their lives" (Service 4), helped the children "develop skills and achieve greater personal control and independence on their lives" (Service 6), encouraged them "to be more meaningfully involved in the world around them" (Service 7), and enabled them "to achieve their maximum individual potential for participation in the community" (Service 10). The statements drew on the notion of multiple systems of health, including but not limited to the physical, psychological, social, and the educational, which aligns with the World Health Organization (1948) definition of health as well as social-political conceptualizations of health and disability (e.g., Finkelstein, 2001; Gabel & Peters, 2004; Marks, 1999; Oliver, 1983; Schalock, 2004).

A holistic definition of health was also present in the vignettes about clients whereby the children were described primarily as "regular" children first, and where the child's impairment and the therapy services they received from the service were secondary. This strengths-based approach is illustrated in the following example from parents of a child in receipt of services from Service 6.

We asked the coordinator [of service] if Alicia could join them, even though it was obvious Alicia could not do the same things as the other four year olds. [The coordinator] welcomed Alicia and encouraged her participation. . . . At the beginning of the season Alicia would walk through each activity as long as someone held her hand. There were some activities she just couldn't do, but for the most part she tried—she was slow and held every one up, but the other kids just moved around her. They were having too much fun to worry about Alicia. The other parents were as encouraging to Alicia as they were with their own kids. By the end of the season Alicia was independently doing the relays, the long jump, and with just a little help, she was getting though the obstacle course. . . . Her skill level improved every week, and along with the skills came confidence and enormous satisfaction. This is what junior sport is all about and Alicia was part of it.

Some of the services emphasized other roles that complemented the provision of therapy. These included professional consultancy, training, and support for families, teachers, and service providers (Service 3), provision of resources and assistance on the purchasing of aids for families and schools (Service 3), fact sheets on various health issues (e.g., child nutrition) (Service 9), and the delivery of health promotion programs (Service 5).

Use of Multidisciplinary Teams

The presence of this indicator ranged from a simple list of the range of health professionals who were employed within the service to an emphasis on health professions working together to provide the best service to clients and their families. An example of the latter is Service 3's "multidisciplinary teams of professionals are committed to improving the quality of children's lives." However, this indicator of wellness was not elaborated on in the analyzed documents.

It is often assumed that the presence of multidisciplinary teams in health care settings results in democratic processes between members and better services (O'Connor, Fisher, & Guilfoyle, 2006; Shaw, de Lusignan, & Rowlands, 2005).

Despite this assumption, moves toward multidisciplinary teams and shared control between disciplines have also been problematic. Research has demonstrated that multidisciplinary health care teams often reveal no improvement in quality of care, communication is frequently unequal and conformist, cultural and professional gaps between disciplines might be widened, and, where medical doctors are members of the teams, they tend to dominate the interaction and decision-making processes (Atwal & Caldwell, 2005; Hiscock & Pearson, 1999; Law & Boyce, 2003; Shaw et al., 2005; Wearing, 1999).

Provision of Support from a Community-Based Setting

The services varied in the degree to which they were community-based. In addition to providing support from within the services' main facilities, six provided services directly in the home (Services 3, 4, 6, 7, 8, and 10), three in child-care settings (Services, 2, 6, and 7), and five to schools and kindergartens (Services 2, 3, 6, 7, and 10). Interestingly, six stated that they provided services within the "community" (Services 1, 3, 4, 6, 7, and 10) without explaining how the community differed from the other settings mentioned. For example, Service 7 worked with children "at home, school, or in the community." Two services provided a rationale for the provision of services within the child's usual environments rather than within their therapy centers. Service 6 explained, "We know that children learn and develop best in an environment in which they are comfortable," whereas Service 10 asserted that "the best possible learning is integrated into their usual routine."

The word *community* appeared numerous times throughout the analyzed documents and the data matrix. However, being based within the community does not make a service of the community (Walker, 1995). The use of the term community implies the existence of mutual obligation and bidirectional influence between each service and the community within which it is situated (McMillan & Chavis, 1986). Despite definitions of community emphasizing relational ties and bonds as well as geographical settings (e.g., McMillan & Chavis, 1986), the services' use of the term tended to pertain to geographical terms, that is, as a place. However, this appropriation of a discourse of community potentially disguises political motives and economic rationalist ideals behind notions of geographic and affective bonds (Saggers, 2005).

With the exception of Service 3, all the services claimed to be state-wide, yet not all explained how their services were provided to children and families residing outside the main cities in which the services were primarily or solely located. Services 4 and 8 had offices or clinics located in large regional towns, and Service 4 also provided visits to children in rural areas and linked these children and their families to local service providers. Services 6 and 10 provided outreach services to rural, regional, and remote areas within their respective states.

Shared Control between Client and Practitioner

The parent(s) of the child and the entire family group were often considered to be the client in addition to the child in receipt of therapy services.

The services stated that their therapists "liaise" (Service 2), "discuss" (Services 2 and 7), and work "collaboratively" (Services 3 and 4) in "partnership" (Services 3, 4, and 6) with the parents and families of the children receiving therapy so that the family has "choice" (Service 6) and "control" (Service 6) and can make "informed decisions" (Service 10) about the services they and their child receive. Service 2 explained this emphasis by stating that their "staff work in a multidisciplinary team. The most important partner in this team is you, the parent or care giver, because you know your child best," and Services 6 and 10 explained that the families are the "experts" when it comes to their own needs, priorities, and well-being. In three cases (Services 3, 6, and 7), the child in receipt of services was also explicitly included in the decision-making partnership, and the remainder focused on the "family" or the "parents" without specifically focusing on the child's role in the process. This is particularly important because children with disability and their parents have been shown to hold differing views concerning service delivery (Garth & Aroni, 2003) and this research demonstrates that the opinions of children with disability should be further explored within the therapeutic partnership.

Four services (Services 3, 4, 6, and 10) stated that their emphasis on shared control and partnership was informed by family-centered practice (Hanna & Rodger, 2002; King, Teplicky, King, & Rosenbaum, 2004; Law et al., 2003). Family-centered practice was defined by Service 6 as the recognition that "families need up-to-date, accurate, and reliable information to make well-informed decisions, work out what they need, [and] decide what they see as most important for the child at any point in time." In this approach, families and therapists "work together in partnership and each has expertise to contribute" (Service 3), services are "developed and implemented in partnership with parents and in collaboration with other professionals" (Service 4), and the role of the professional is to provide family members with information so they can make "informed decisions" (Service 10) and "achieve what they decide are their priorities" (Service 6).

By stating that they assist "children, young adults and their families achieve their full personal potential and help them become empowered to make informed choices about their lives," Service 7 appeared to work from an empowerment model (e.g., Melnyk et al., 2004; Newman & Vidler, 2006). However, no further information was supplied, nor was there any attention to the power differential between parents and professionals that can counteract the development of working partnerships between them (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004), the conflation of family involvement in care with family responsibility for care (Dodd et al., 2007; Shields, Pratt, & Hunter, 2006) or to research indicating that parents believe family-centered practice has more negative outcomes than do service providers (King, Kertoy, King, Law, Rosenbaum, & Hurley, 2003).

The assumed expertise of parents of children with disability was also illustrated in the corporate governance of Service 6, where five of the nine board members, including the president and vice president, are parents of present or former clients of the service. Some commentators (e.g., Finkelstein, 2001; Townsend, 2003) have proposed that clients should have a critical role in service delivery and professional organizations and there is a trend more

generally toward user-led disability services (Barnes & Mercer, 2006). The increased involvement in and control of disability services by people with disability and their families is thought to have the potential to challenge the status quo that only "abled" people can administer services to people with disability (Finkelstein, 2001).

Individualized Support, Therapy, and Intervention

This indicator was mentioned to some degree or another by five services (Services 3, 4, 6, 7, and 10). The rationale for individual planning and programming was explained by Service 6 as "no two children are the same, so services are individualised, responsive, and flexible." Service 3 outlined the difficultly of meeting individual needs within the context of funding: "The long term challenge remains to evolve towards a business model that reduces dependency on government funding and [at the same time] enhances opportunities to provide new and flexible services tailored to the perceived needs of families, rather than the bureaucratic convenience of funding programs." Individualized support, as opposed to a "one-size-fits-all" approach to service delivery, is considered to be a key characteristic of appropriate disability approaches (Schalock, 2004; Umbarger, Stowe, & Turnbull, 2005).

Advocacy and the Politicization of Health

Some services stated that an aim was "to advocate on health issues of behalf of the women and children of [state]" (Service 1) and "be regarded highly as a valued advocate to policy decision makers" (Service 7). Others were more specific about the ways they provide advocacy and rationale behind it. For example, drawing on the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (2001), and the notion that disability might result from social and environmental barriers, Service 6 might "recommend or arrange: ramps for building access, building modifications to provide accessible toilets, [and] training in communication interaction strategies to enhance communication opportunities for children." Likewise, to better met the needs of blind and visually impaired people, Service 4 maintained an active advocacy role by developing public policy positions in various areas included outdoor dining, education and training, print standards, and safe and accessible public transport. In relation to this indicator of wellness, the services tended to participate in advocacy far more than the politicization of health and disability. Some commentators have recently argued that the "political" is often absent from social-political approaches and have proposed the development of a resistance theory of disability that is explicitly emancipatory (e.g., Gabel & Peters, 2004; Watson, McKie, Hughes, Hopkins, & Gregory, 2004).

CONCLUSION

Wellness remains a largely elusive and contested term in the literature (Breen et al., in press; Kahn & Juster, 2002; Larson, 1999). Part of the explanation is

the continuing tensions between the social-political, medical, and economic paradigms that underpin Australian health care policy and practice (Bowles, 2001). Importantly, these competing and contrasting pressures are evidenced by the ways in which the childhood health and disability organizations describe their service delivery, which helps explain the difficultly of shifting from wellness rhetoric to reality.

Determining where and how wellness appeared in the Web sites, annual reports, and strategic plans of the selected childhood health and disability services was further obscured by the lack of any reference to the term wellness. That is, despite the growing use and acceptance of the term, it did not appear even at the rhetorical level in the selected documents of major childhood health and disability providers across Australia. Furthermore, while all six correlates of wellness were mentioned, at least to some degree, how each characteristic was enacted by and practiced within each by service remains unclear. This uncertainty illustrates the importance of moving beyond the rhetoric of wellness and exploring how such a concept is implemented in practice. Ultimately, the shift requires holistic and complex changes to allied health professional education and training, practice, and research, as well as funding structures and practices that determine the delivery of childhood health and disability services (Breen et al., in press).

Although the services appeared to endorse at least some or all of the wellness correlates, the rhetoric may not always match the reality of service provision (Bowles, 2001; Goodgold, 2005; Hanna & Rodger, 2002; Saggers et al., 2002; Schalock, 2004; Wearing, 1999). The alignment of allied health literature on health and disability with policy and practice is integral to the improvement of health and disability services. Embedding wellness approaches into health and disability services requires holistic and complex action within allied health professional education and training, practice, and research, rather than just a change in the terminology and rhetoric used. The details of this action in each context need to be identified.

The next stage in our ongoing research involves in-depth case studies of four major childhood disability service providers in Australia to determine how wellness approaches are embedded within the practices of these services and examine the factors that facilitate and impede their implementation. The proposed outcome of the research program is the development of guidelines for the practice of wellness across allied health services. Although based in Australia, the research is relevant to all contexts where the contemporary literature and current policy/practice are misaligned, providing a significant step toward the provision of childhood health and disability services that are more readily empowering and that addresses issues of client well-being, individual choice, independence, and the right to meaningful and productive lives.

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REFERENCES

- Atwal, A., & Caldwell, K. (2005). Do all health and social care professionals interact equally: A study of interaction in multidisciplinary teams in the United Kingdom. Scandinavian Journal of Caring Sciences, 19, 268–273.
- Australian Institute of Health and Welfare. (2006). Disability updates: Children with disabilities. Bulletin no. 42. Cat. no. AUS 19. Canberra, Australia: Author.
- Barnes, C., & Mercer, G. (2006). Independent futures: Creating user-led disability services in a disabiling society. Bristol: Policy Press.
- 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.
- Bowles, W. (2001). The Australian disability field—Times of change. In M. Alston & J. McKinnon (Eds.), *Social work: Fields of practice* (pp. 33–45). Melbourne: Oxford University Press.
- Breen, L. J., Green, M. J., Roarty, L., & Saggers, S. (In press). Towards embedding wellness approaches to health and disability in the policies and practices of allied health providers. *Journal of Allied Health*.
- Burgess-Limerick, T., & Burgess-Limerick, R. (1998). Conversational interviews and multiple-case research in psychology. *Australian Journal of Psychology*, 50, 63–70.
- Dodd, J., Saggers, S., & Wildy, H. (in press). Constructing the ideal family for family centered practice: Challenges for delivery. *Disability and Society*, 24.
- Finkelstein, V. (2001). Disability: A social challenge or an administrative responsibility? In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers*, enabling environments (pp. 34-43). London: Sage.
- Gabel, S., & Peters S. (2004). Presage or paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability and Society*, 19, 585–600.
- Garth, B., & Aroni, R. (2003). "I value what you have to say." Seeking the perspective of children with a disability, not just their parents. *Disability and Society*, 18, 561–576.
- Goodgold, S. (2005). Wellness promotion beliefs and practices of pediatric physical therapists. *Pediatric Physical Therapy*, 17, 148–157.
- Hanna, K., & Rodger, S. (2002). Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration. Australian Occupational Therapy Journal, 49, 14–24.
- Hiscock, J., & Pearson, M. (1999). Looking inwards, looking outwards: Dismantling the "Berlin Wall" between health and social services? *Social Policy and Administration*, 33, 150–163.
- Jones, G. C., & Kilpatrick, A. C. (1996). Wellness theory: A discussion and application to clients with disabilities. *Families in Society: Journal of Contemporary Human Services*, 77, 259–267.
- Kahn, R. L., & Juster, F. T. (2002). Well-being: Concepts and measures. *Journal of Social Issues*, 58(4), 627-644.

- 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-centered service for children with cerebral palsy and their families: A review of the literature. Seminars in Pediatric Neurology, 11, 78-86.
- Krahn, G. L., Putnam, M., Drum, C. E., & Powers, L. (2006). Disabilities and health: Towards a national agenda for research. *Journal of Disability Policy Studies*, 17, 18–27.
- Larson, J. S. (1999). The conceptualization of health. Medical Care Research and Review, 56, 123-136.
- Law, D., & Boyce, R. A. (2003). Beyond organisational design: Moving from structure to service enhancement. *Australian Health Review*, 26, 175-185.
- Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., et al. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health and Development*, 29, 357–366.
- Marks, D. (1999). Disability: Controversial debates and psychosocial perspectives. London: Routledge.
- McMillan, D. W., & Chavis, D. M. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*, 14, 6-23.
- Melnyk, B. M., Alpert-Gillis, L., Feinstein, N. F., Crean, H. F., Johnson, J., Fairbanks, E., et al. (2004). Creating opportunities for parent empowerment: Program effects on the mental health/coping outcome of critically ill young children and their mothers. *Pediatrics*, 113, 597–607.
- Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: An expanded sourcebook (2nd ed.). Thousand Oaks, CA: Sage.
- Murray, S. (2007). Families' care of their children with severe disabilities in Australia. *Community, Work and Family, 10,* 215–230.
- Newman, J., & Vidler, E. (2006). Discriminating customers, responsible patients, empowered users: Consumerism and the modernisation of health care. *Journal* of Social Policy, 35, 193–209.
- O'Connor, M., Fisher, C., & Guilfoyle, A. (2006). Interdisciplinary teams in palliative care: A critical reflection. *International Journal of Palliative Nursing*, 12, 132–137.
- Oliver M. (1983). Social work with disabled people. London: Macmillan.
- Robson, C. (2002). Real world research (2nd ed.). Malden, MA: Blackwell.
- Saggers, S. (2005). Negotiating definitions of Indigenous participation in community development. In R. Eversole & J. Martin (Eds.), *Participation and governance in regional development* (pp. 195–210). Aldershot: Ashgate.
- Saggers, S., Paskevicius, A., Tilley, F., Payne, L., Ghose, A., Wildy, H., et al. (2002). Changing models of care: Tools towards best practice for consumers and professionals in the paediatric disability and health service sectors. Perth, Australia: Edith Cowan University.
- Schalock, R. L. (2004). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies*, 14, 204–215.
- Shaw, A., de Lusignan, S., & Rowlands, G. (2005). Do primary care professionals work as a team: A qualitative study. Journal of Interprofessional Care, 19, 396-405.
- Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: A review of qualitative studies. *Journal of Clinical Nursing*, 15, 1317–1323.
- Thoreau, E. (2006). Ouch! An examination of the self-representation of disabled people on the Internet. *Journal of Computer-Mediated Communication*, 11, 442–468.
- Townsend, E. (2003). Reflections on power and justice in enabling occupation. Canadian Journal of Occupational Therapy, 70(2), 74–87.

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.

- Umbarger, G. T., Stowe, M. J., & Turnbull, H. R. (2005). The core concepts of health policy affecting families who have children with disabilities. *Journal of Disability Policy Studies*, 15, 201–208.
- Walker, P. (1995). Community based is not community: The social geography of disability. In S. J. Taylor, R. Bogdan, & Z. M. Luftiyya (Eds.), The variety of community experience: Qualitative studies of family and community life. Baltimore, MD: Brookes.
- Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter) dependence, needs and care: The potential for disability and feminist theorists to develop an emancipatory model. *Sociology*, 38, 331–350.
- Wearing, M. (1999). Medical dominance and the division of labour in the health professions. In C. Grbich (Ed.), *Health in Australia: Sociological concepts and issues* (pp. 197–216). Sydney: Prentice Hall.
- World Health Organization. (1948). Preamble to the constitution of the World Health Organization. Retrieved on October 11, 2007, from www.searo.who.int/LinkFiles/About_SEARO_const.pdf.
- World Health Organization. (2001). International classification of functioning, disability and health. Geneva: Author.