

Types of support accessed by families of young children with disabilities living in Alberta

Jane Drummond, Linda McDonald, Sandra MacKenzie-Keating, &

Darcy Fleming
University of Alberta
Maurice A. Feldman
Brock University
Rick Enns
University of Calgary

This longitudinal study inventoried the types of services accessed by a sample of Alberta families of children with or at-risk for disabilities. We explored the role of severity of disability, parental stress, and family income on services accessed. With few exceptions, services were accessed more frequently as the children's lives progressed but higher income families accessed more services than lower income families, even though the latter families had children with more severe disabilities. Difficulties accessing services and lack of services were reported by lower income families. The authors conclude that integrated services are necessary to improve access for those families most in need.

Background

Approximately 564,575 or 7.7% of Canadian children and youth from birth to 19 years of age have an activity limitation or a disability, including physical, psychological and mental disabilities (Canadian Institute of Child Health [CICH], 2000; National Population Health Survey, 1996-1997). When the definition of disability is broadened to include activity limitation and "special needs," 9.3% of Canadian children have one or more disabilities (National Longitudinal Survey of Children and Youth [NLSCY], 1996). The Roehrer Institute of Research (2000) confirms that between 5% and 20% of Canadian families have children with disabilities and, among children with disabilities, 15% (more than 80,000 children) have a moderate or severe level of disability. In comparison, between 15% and 20% of American children and adolescents live with a chronic physical, developmental, behavioral or emotional disability (Newacheck et al., 1998).

In Canada, most children with disabilities are living at home with their families and families are expected to accept an increasing amount of responsibility for the care and well-being of their children (Brown, 1999; Renwick, Brown, & Raphael, 1997). Only partial data are available for these children and their families. They are potentially more vulnerable than other children and often “fall through the cracks” of health, social services, education and recreation systems that support healthy child development (CICH, 2000). Fragmented health and social services require parents of children with special needs to take on advocacy and coordinating roles to access necessary services (Ray, 2002; Sloper, 1999; Valentine, 2001). The resulting parental distress associated with this role influences family functioning and impacts on children in many ways, including cognitive, behavioural and social development (Richman, Stevenson, & Graham, 1982; Wallander & Varni, 1998).

There is considerable variation in the way a family appraises the stress associated with having a child with a disability and it is not explained by the severity of the disability (Sloper, 1999). Material, personal and social resources relate strongly to parental well-being (Frey, Greenberg, & Fewell, 1989; Sloper & Turner, 1993; Sloper, Knussen, Turner, & Cunningham, 1991; Wallander, Varni, Babani, DeHaan, Wilcox, & Bannis, 1989), while inadequate income, housing, and transportation are associated with increased levels of distress (Sloper & Turner, 1993; Sloper, et al., 1991). Families of children with disabilities have lower incomes and less external maternal employment than families without children with disabilities (Beresford, 1995; Gordon, Parker, & Loughran, 1996; Sloper et al., 1991).

Numerous services are now available to support families of young children with disabilities. Early intervention may involve an array of services and supports including service coordination; parent education; physical and occupational therapy; medical specialists; visiting nurse; nutrition, speech and language therapy; behaviour management; family counseling; specialized preschool; financial aide; child-care and respite care (Bruder, 1997; Dinnebeil, 1999; Harbin, McWilliam, & Gallagher, 2000).

Several studies have used Bronfenbrenner’s (1979) ecological model to investigate child, parent, family, and service characteristics and other factors associated with service utilization in families of young children

with disabilities. Child characteristics related to increased early intervention service utilization include severity of disability and age, for example, preschoolers tend to receive more intervention than infants (Kochanek & Buka, 1998). Parent characteristics related to increased family service utilization include coping skills (Gavidia-Payne & Stoneman, 1997), education level (Kochanek & Buka, 1998) and self-efficacy (Bailey et al., 1998). Family variables associated with service use include socio-economic status (poor families access fewer services), knowledge of the service system, and ongoing advocacy for services (Bailey et al., 1998; Dunst & Trivette, 1997). Services that are culturally sensitive, flexible, use best practices, and promote parental empowerment and involvement tend to have higher utilization rates (Harbin et al., 2000).

Many early intervention services now endorse a “family-centered” approach that emphasizes family support and parent education in addition to specific services related to the child’s disability (Trivette, Dunst, Boyd, & Hamby, 1995). One assumption of these programs is that beneficial effects will accrue not just to the child, but also to the parents, siblings, and the family as a whole (Feldman, 2004). Results to date are equivocal: Some studies have reported improvements in parent and family distress related to involvement in early intervention (Erickson Warfield, Hauser-Cram, Wyngaarden Krauss, Shonkoff, & Upshur, 2000) while others have not (Mahoney & Bella, 1998).

Virtually all our knowledge of early intervention service utilization originates in the United States. Little is known about the Canadian experience. The goal of this study is to begin to document early intervention service utilization in Canadian provinces, in this case, Alberta. We will examine the types of services accessed by a sample of Albertan families of children with or at-risk for disabilities over the first four years of the child’s life. We will explore the relationship between the severity of the child’s disability, parental stress, and family income on services accessed.

Research Questions

1. What are the child and family services accessed by families of children with disabilities or at-risk for disability from birth to 4 years of age and how does service use change over time?

2. What is the nature of, and the relationship between, severity of disability, parental stress and family income in families of 2-year-olds with disabilities or at-risk for disabilities?
3. What is the effect of severity of disability, parental stress, and family income on type of services accessed by families of 3-year-olds with or at-risk for disabilities?

Methods

Participants

Participants were recruited from a regional hospital providing rehabilitation services and assessment for young children and their families, an early intervention program for children with developmental disabilities, and an early intervention program for young children at-risk for developmental disabilities. Sixty-six 2-year-old children from 63 families participated in the first year of the longitudinal study. All children had or were at-risk for a developmental delay, and some had accompanying medical (e.g., epilepsy, compromised immune systems), motor (cerebral palsy, spina bifida), and sensory (e.g., hearing, vision) problems.

Parents reported that 30% of the children had no formal diagnosis at 2 years of age. The remaining children had a variety of diagnoses including developmental disability cause unknown, learning disability, Down syndrome, cerebral palsy, spina bifida, epilepsy, brain damage, autism, fetal alcohol effect, other genetic conditions, and multiple diagnoses. By 4 years of age 22% of the children were still without a formal diagnosis. Parents reported that 88% of the children were in good to excellent health most or all of the time. Thirty-eight percent of the children were born after less than 37 weeks.

Ninety-five percent of the children were living with their natural parents and 88% were in two-parent families. Fifty-nine percent of the children were male. Most children (96%, $n = 63$) resided in urban settings. The mean number of adults living in the home was two (range = 1-4) and the mean number of children in the home was two (range = 1-6).

Eighty-two percent of the parents answered the family income question: 22% reported an income less than \$30,000, 46% reported an income

between \$30,000 and \$60,000, and 33% reported an income greater than \$60,000. The mean age of the mothers was 33 (range = 22-48) and the mean years of education was 14 (range = 9-19). Forty-seven percent ($n = 31$) of mothers were working full time in the home while the remainder worked outside of the home either full- or part-time. The fathers were slightly older ($M = 36$, range = 25-51) with similar levels of education as the mothers ($M = 13$; range = 8-21). Most fathers (86 %, $n = 57$) worked outside of the home.

Sixty-one children from 58 families continued to participate in the second year of the study and 59 children from 56 families participated in the third year of the study. Attrition rate over the three years of the study was 9%. Fifty-five children from 52 families had complete data on a majority of measures across all three years of the study. Because we were interested in the use of services over time, most analyses in the present study were conducted only on the 55 cases with complete data over the three years of the study.

Data Collection

Two research assistants collected all of the questionnaire data. The research assistants were both graduate students in special education and received specific training in family-centered assessment. They also received training on administration of each of the questionnaires.

Data were collected in the home when children were approximately 2, 3, and 4 years of age. At age 2 and 4 years, parents completed 15 questionnaires that assessed a variety of child and family variables, including child development and behaviour, stress, social support, coping strategies, behaviour management strategies, and service utilization. Child development was assessed by a trained psychological assistant under the supervision of a chartered psychologist, at 2 and 4 years of age.

Home visits were conducted at the convenience of the parents. Each year, data were collected over two to three home visits. Informed consent was obtained at the beginning of each year. Parents were reminded that they could refuse to answer individual questions on questionnaires, complete particular questionnaires, have their interactions videotaped, or have their child's development assessed.

Each visit lasted between two and four hours. During the visit, a research assistant asked the parents to complete the questionnaires. Assistance was provided as necessary. In some instances, when needed, the questionnaires were read to the parents. Following completion of the questionnaires at age 2 and 4, videotaping and child development assessments were completed. At age 3 and 4, questionnaires were mailed to the family homes in advance of the home visit. Parents had the option of completing some of the questionnaires prior to the visit. The research assistant would then help the parents with questionnaires that required interviews, and videotape parent-child interactions if required.

Retention

Several things were done to encourage families to continue to participate over the three years of the study. Project staff maintained personal contact with the families throughout the study. Research assistants made phone calls to parents between visits and sent birthday cards to the children. Two research assistants collected all of the data. At the beginning of the study, each research assistant was assigned to one-half of the families. When one research assistant was unable to continue part-way through year 3, the second research assistant collected the remainder of the data for the families. The same individual collected all of the child development data throughout the 3-year study. We believe that this personal contact helped maintain parent interest in the research study. In addition, parents were paid a yearly \$50 honorarium at the completion of data collection regardless of how much data were collected. At the end of the study, parents received a videotape of the child and parent interactions at 2 and 4 years of age. Perhaps most important, parents often expressed satisfaction with the opportunity to share information and possibly help other families.

Instruments

Family Information Questionnaire. Parents were asked to provide basic demographic information on their child such as age, sex, birth order, diagnosis, medication, illnesses, and hospitalizations. The questionnaire also included parent information such as age, education, marital status, illnesses, number of children, living arrangements, family income, and

occupation. Family income was reported at 2 years and was categorized into: low-income of less than \$30,000; medium-income of \$30,000 to \$60,000; and high-income of greater than \$60,000 per year.

The Bayley Scales of Infant Development - Second Edition (BSID-II) - Mental Scale and Motor Scale (Bayley, 1993). The BSID was used in this study as a measure of child development. The BSID is appropriate for children up to 42 months of age (although it can be used for slightly older children with known delays). It consists of Mental Development and Motor Development Indices (as well as the Infant Behavior Development Record which was not used in this study). It correlates well with the Stanford Binet Intelligence Scale, and is considered the best measure of early intellectual development (Sattler, 2002). The BSID scores gathered from children at 2 years of age were used in the analysis of data. For the purposes of this study children with scores less than 70 were categorized as low functioning. Those with scores between 70 and 84 were regarded as medium functioning and children with scores greater than 84 were categorized as high functioning.

Parenting Stress Index (Short Form). The Parenting Stress Index Short Form (PSI/SF: Abidin, 1995) is a simplified version of the 1978 questionnaire that captures the impact of dysfunctional parent-child interaction on subsequent parenting behaviour more directly. The PSI/SF consists of 36 statements and possible responses on a Likert-type scale between 5 (strongly agree with statement) and 1 (strongly disagree with statement). The three subscales of the PSI/SF are labeled Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. The questions are divided into a Parent Domain and a Child Domain. The PSI/SF yields a stress score for each subscale and an overall stress score. Numerous studies have confirmed the reliability and validity of the PSI long form. While the empirical validity of the PSI/SF model has not been fully established, clinical experience and other research on the same conceptual variables suggests that the model is viable (Abidin, 1995). Scores less than 55 were categorized as low stress. Scores between 56 and 85 were classified as medium stress and scores above 86 were categorized as high stress.

Service Questionnaire. We devised a service questionnaire based on a review of early intervention literature. This scale lists the scope of services and supports that could be provided to families with children

at-risk for disabilities and provided space to describe additional services. Listed services included medical (e.g., family physician, pediatrician, neurologist), special therapeutic services (e.g., speech therapy, physiotherapy, behavioral), developmental/preschool related services (e.g., infant development program, day care), and family services (e.g., parent education, respite care, family support worker). Information about duration, intensity, location, parental involvement, need for, satisfaction with, and perceived effectiveness of each service received was solicited. The last four items are rated on a 7-point Likert scale.

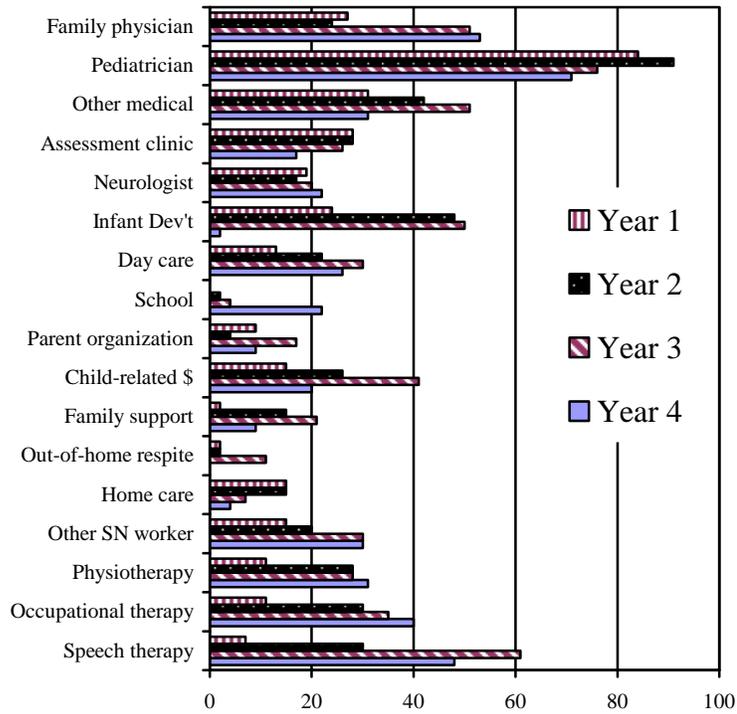
Twenty-one of the listed services on the Service Questionnaire were utilized in this analysis. Four service items reported to be used by less than 10% of the participants each year were eliminated from the analysis (e.g., psychiatrist, massage therapist, visiting nurse, parental counselling). The remaining 17 items were divided into child-focused and family-focused service categories. The child service category included medical services, special therapeutic services, and development/school-related services. To answer the first research question, the percentage of children and families using each categorized service item was visually displayed for each year using bar charts.

Findings

Service Utilizations

Services accessed from birth to 4 years are presented in Figure 1. Use of family physicians increased to 50% by the fourth year while use of pediatricians remained high (range = 70-90%). Use of other medical personnel went up over the first three years and down to about 50% by year 4. Access to assessment clinics and neurologists remained constant at about 30% and 20%, respectively, across the four years of the study. Use of special therapeutic services (speech therapy, occupational therapy, physiotherapy and other special needs practitioners) went up consistently across the years, with speech therapy being used most often. Development and school-related services went up over time in all cases, with infant development programs falling dramatically during the fourth year. Family service use was varied. Home care was used very little and early (15% of families in years 1 and 2). The remaining family services (respite, family support worker, financial support for child-related needs, and participation in parent organizations) went up for the first 3 years and dropped during the fourth year of data collection.

Figure 1: Percentage of Families Accessing Services by Year
(n = 46)



Note: Medical services include family doctor, pediatrician, neurologist, assessment clinic, other medical; *special needs services* include speech pathology, occupational therapy, physiotherapy, other special needs worker; *development & school-related services* include infant development, day care, school; *family services* include home care, out-of-home respite, family support worker, funding for child-related needs, parent organizations.

Relationship between severity of disability, parental stress, and family income

Based on the BSID, 54% (n = 30) of the children were categorized as low functioning, 22% (n = 12) as medium functioning, and 24% (n = 24) as high functioning. The PSI results showed that the majority of parents

experienced medium to high parental stress: 28% ($n = 20$) had medium stress, 44% ($n = 23$) had high stress, and 17% ($n = 9$) had low stress. Family income was low for 22% ($n = 12$) of families, medium for 47% ($n = 26$) and high for 31% ($n = 17$). The number of families reporting on each variable was influenced by the source of data. Loss of data was higher for family income and parental stress because these were determined through self-report and self-reporting was less complete. Data for severity of disability were more complete because independent certified psychologists collected these data separate from the interview process. Mean severity of disability was related to family income ($p < .05$). However, no relationship was significant between paired categories of severity of disability by parenting stress and/or by family income.

Severity of disability, parental stress, family income and types of services accessed

Visual examination of the bar graphs for services accessed at year 3 by severity of disability shows two interesting trends: families with low functioning children use fewer services than families with high functioning children in eight of the 17 or 47 % of the services analyzed, and families with children with moderate functioning access services less often than families with low and high functioning children in 11 of the 17 services or 65% of the time. Only four of the 17 services were used incrementally more as the category of parental stress moved from low to high (family physician, speech therapy, other special needs worker, and family support worker). Two services were used incrementally less as parental stress moved from low to high (neurologist and financial support related to child need). Ten of seventeen services or 60% were used more often by moderately stressed parents than by either low or highly stressed parents of children with disabilities. Finally, low-income families accessed less service than medium- and high-income families in 12 of the 17 services analyzed or 71% of the time. Most dramatic is the complete lack of access by low-income families to respite and assessment services.

Support accessed for children with disabilities 11

Figure 2: Percentage of Families Accessing Services at Year 3 by Severity of Disability (n = 46)

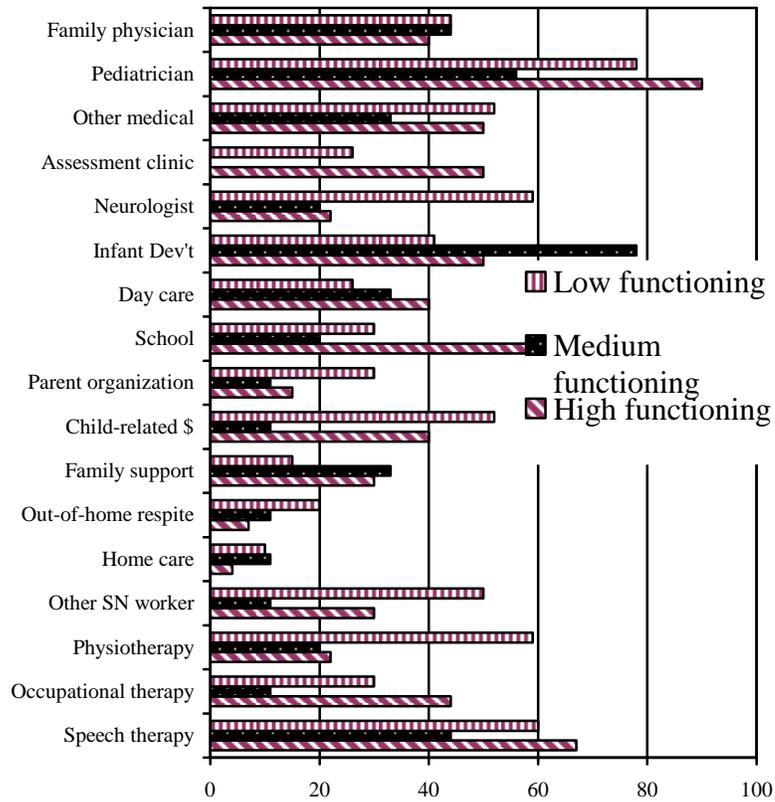


Figure 3: Percentage of Families Accessing Services in Year 3 by Parental Stress (n = 46)

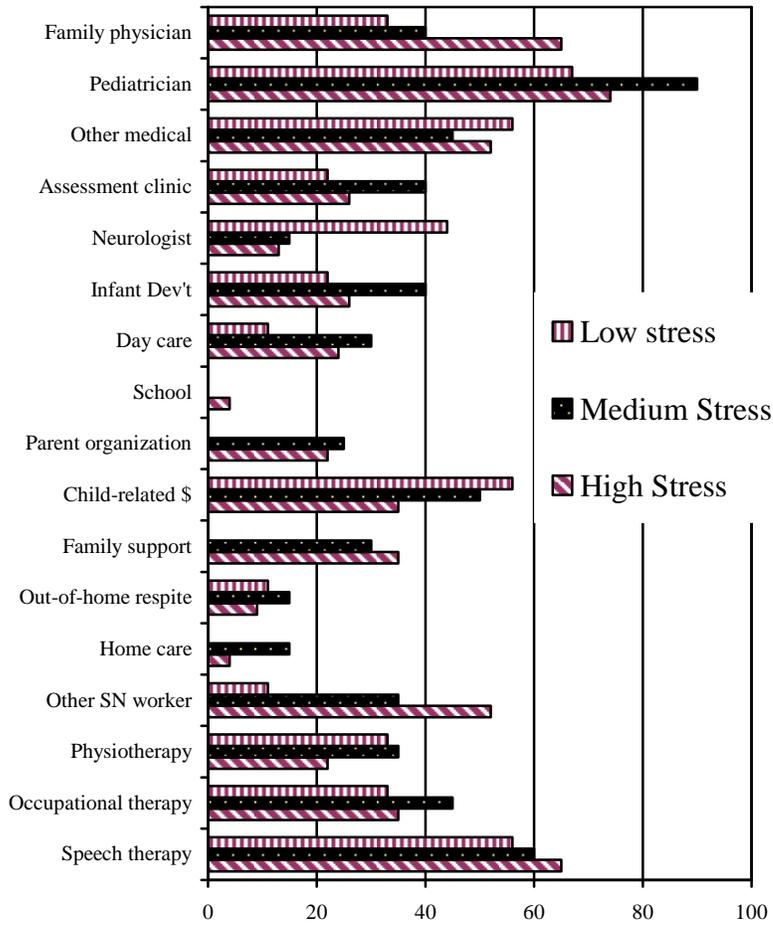
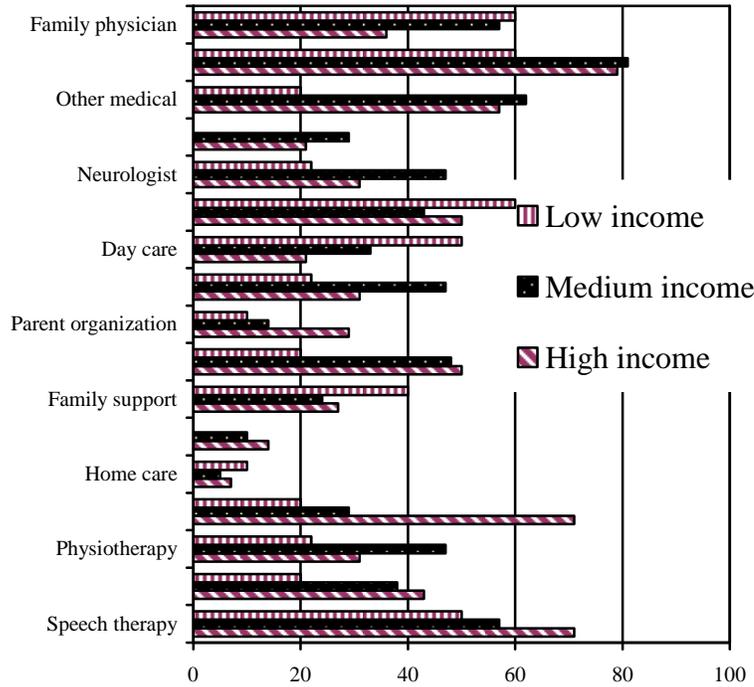


Figure 4: Percentage of Families Accessing Services in Year 3 by Family Income
(n = 46)



Discussion

We sought to answer three questions with this research: (1) What types of services are accessed by families of children with disabilities/special needs or at-risk for disability from birth to 4 years of age? (2) What is the nature of, and the relationship between, severity of disability, parental stress and family income in families of 2-year-olds with disabilities/special needs or at-risk for disability? and (3) What is the effect of severity of disability, parental stress, and family income on the type of service accessed by these families?

The results of this study are consistent with ecological models of disability (e.g., Crnic, Friedrich, & Greenberg, 1983) that suggest the impact of disabilities on parents and families depends not only on the nature of the disability but also on family characteristics. With few exceptions, services polled in this study were accessed more frequently as the first four years of the children's life progressed. The majority of the children in the sample were reported to have low functioning or severe disabilities. Severity of disability did not systematically relate to services accessed by families. Parents who experienced moderate parental stress accessed services more frequently than those with either high or low parental stress. Family income, on the other hand, was related to services accessed by families. High-income families accessed more services, despite the fact that low-income families had children with more severe disabilities.

The needs of families and children with disabilities are constantly changing and the services they require change in corresponding ways. (Brown, Anand, Fung, Isaacs, & Baum, 2003). Most services accessed in this study changed over time as expected. Similar service utilization has been reported in previous studies (Floyd & Gallagher, 1997; Haveman, vanBerkum, Reijndewrs, & Heller, 1997). For instance, in a study of families of children with mental illness, Haveman and colleagues reported that, in the first nine years, three-quarters of parents needed direct support for their child and themselves, advice about developmental issues, assessments for the child with a disability, and information and advice from a physician. Referrals to a dietitian, speech therapy, emotional support, and respite services were also reported as needs by over one-half of parents in that study.

Although referrals for services are often related to the severity of the problem (Campbell, Gardner, & Ramakrishnan, 1995), the severity of disability did not systematically predict service utilization in this study. Fifty percent of the children had severe disabilities or were categorized as low functioning as measured on the Bayley Scales of Infant Development. These families used fewer services than families whose children had lower levels of disability or were high functioning, while families of children with a moderate disability utilized even fewer services than either low or high functioning children.

Parental stress in families who have a child with a disability is a result of juggling work and family, with child care responsibilities. High levels of stress put the health and well-being of parents, and the parent-child relationship, at risk and even moderate levels can compromise quality of life. Appropriate services and supports, if widely available, could reduce these levels of stress (Irwin & Lero, 1997). The majority of parents (72%) in this study reported high to medium parental stress. These stress levels are somewhat lower than the 93% reported by the Canadian Institute for Child Health (2000). As in other studies (Haveman et al., 1997), our data show less service use associated with high parental stress.

In this study the severity of the child's disability was inversely related to family income. This association of low-income with high disability or low functioning is compounded by reduced access to services by low-income families. These data are consistent with the findings that families who receive the least services are often those with the greatest social needs: single parents, large families, and low-income families (Brown et al., 2003; Sloper, 1999). Families of children with a disability often face higher health-related costs, lack of employment, and poverty, than do similar households with children with no disability. Women are especially impacted upon as they are responsible for the majority of care-giving (Canadian Association for Community Living, 2003).

Socioeconomic factors are serious barriers for families caring for a child with disabilities, especially those living on social assistance (Valentine, 2001). Barriers for low-income families include lack of time to find needed services due to other responsibilities, limited finances, unavailability of transportation, low social support and lack of respite (Brown et al., 2003). These families have been described as families "whose voices are seldom heard, and whose circumstances and struggles are systematically made invisible" (Roehrer Institute, 2000, p. 45). Low-income parents' ability to communicate their needs and to maneuver within the system may also influence the level of service utilization (Fox, Wicks, & Newachek, 1993). On the other hand, service providers also provide barriers to low-income families of children with disabilities. These include absent or inadequate marketing, fragmentation, narrowness of mandate, complex and inconsistent eligibility criteria, power differentials created by provider expertise, geographic inaccessibility, language barriers, hours of availability, reduction of service at schooling transition points, and service culture (Ray, 2005).

Unmet Needs

An analysis of an open-ended question in the Services Questionnaire asking about unmet service needs reveals that many family participants in this study reported unmet needs for services. Lack of knowledge about services, services not available in their community, or long waiting lists, are reported as reasons for not accessing needed services. A review of the literature finds that parents' views of their unmet needs and those needs that are most frequently unmet have changed little in the past 25 years (Beresford, 1995; Betz, Baer, Poulsen, Vahanvaty, & Bare, 2004; Brown et al., 2003; Ray, 2002; Sloper, 1999; Sloper & Turner, 1992). More than one-third of parents report similar unmet needs, including guidance about available services, information concerning their child's disability, direct advice on how to help their child (Betz et al., 2004; Brown et al., 2003; Farmer, Clark, & Marien, 2003; Farmer, Wendi, Clark, Sherman, & Selva, 2004; Perrin, Lewkowicz, & Young, 2000; Ray, 2003), financial and practical support with housing and transportation, and respite care (Brown et al., 2003; Sloper, 1999; Sloper & Turner, 1992).

Children with disabilities face many obstacles to complete care, including absence of appropriate referrals for associated problems such as nutrition, dental health, mental health, and other services frequently required by this population (Betz et al., 2004; Fox et al., 1993; Newacheck et al., 1998). Betz and her colleagues report that the primary service barrier for all services is a lack of information, a result found in other studies (Brown et al., 2003; Diehl, Moffitt, & Wade, 1991; Garwick, Kohrman, Wolman, & Blum, 1998; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989). Availability of needed services is the second most frequently identified barrier (Betz et al., 2004). There is an uneven distribution of services for children with special needs and their families across Canada (Tan, Hollander, & Hayes, 2000). Provision and coverage of health care and disability-related services are inconsistent and sometimes inadequate in communities across the country (Canadian Association for Community Living, nd).

Many parents experience difficulty finding out what services are available, to understand the roles of each agency and their workers, to know who to go to, and how to communicate their needs (Beresford, 1995; Sloper, 1999). Other families state that the knowledge of, or

guidance from, health care providers regarding available services greatly affected the services that they actually received (Brown et al., 2003). The short-term nature of services is also a consistent complaint. Parents' sense of control: to feel in control that they are of events and able to obtain needed help for family and child is an important personal resource (Frey et al., 1989). Parental burden and stress in interaction with service providers may erode this sense of control (Beresford, 1995; Farmer et al., 2004).

Implications for Practice

In order to reduce barriers both in the provider environment and in families, a two-pronged approach is proposed. First, providers of service need to develop a service environment conducive to collaboration between providers and partnering with families. Second, all aspects of family health literacy must be systematically enhanced within the services delivered.

Inter-sectoral collaboration.

Historically, service providers and service agencies have assigned clients according to their service domains and professional expertise (Short & Talley, 1999). Client needs existing outside the sphere and expertise of individual agencies or professionals often result in referrals or simply did not get addressed. This traditional single-profession, single-setting service delivery model perpetuates fragmented service conceptualization and delivery (Short & Talley, 1999). Children with disabilities and their families require interventions from many different services, such as health, education, and social services, and frequently they experience a lack of coordination between these various agencies that results in confusion for, and increased demands upon, parents (Gordon et al., 1996; Ray, 2002; Sloper & Turner, 1992).

Families report having greater difficulty with the system structure than with the individual health professionals (Ray, 2002). Ray reported that parents wished for a system "that treated their child as a whole person rather than each discipline or service claiming a piece" (p. 428). Families complain about gaps and overlaps in services and a lack of funding for in-home care. Families identify a need for co-ordination and integration of services. A key assumption underlying integrated health services for children is that children's needs transcend professional and agency

boundaries (Short & Talley, 1999). Service integration has been defined as “a process by which two or more entities establish linkages for the purpose of improving outcomes for people” (Konrad, 1996, p.6), through solving the problems of service fragmentation as well as the frequent mismatch between the needs of children with disabilities and their families, and available services (Kahn & Kamerman, 1992). The provision of integrated services can only be achieved through partnerships among families, professionals, and agencies (Bailey et al., 1998).

Because the issues facing both low-income families and families of children with disabilities are rooted in an array of social, economic, and political conditions that extend beyond the control of any one service sector, government and community systems must collaborate to coordinate programs. Collaborations are necessary when organizations share a common purpose, and when that common purpose addresses a meta-level problem (Chisholm, 1996) such as the health of children with disabilities. Collaboration occurs when a group of autonomous stakeholders, sharing a problem domain, interact using shared rules, norms, and structures to address issues related to that domain (Harris, Wise, Hawe, Finlay, & Nutbeam, 1995). In contrast to cooperation, where organizations work together to achieve common day-to-day goals of their organizations, collaboration leads to joint planning and intensive changes in ways of working (Swann & Morgan, 1992). Inherent in collaboration is the notion that the outcomes achieved are more effective, efficient, and/or sustainable than what would have been achieved if organizations were working alone (Browne et al., 1999; Browne & Roberts, 2002; Huxham & Vangen, 2000; Lasker, Weiss, & Miller, 2001; Organization for Economic Cooperation and Development, 2000). Collaborations in the public sector have become more commonplace (Gray & Wood, 1991; Healey, 1997; Jennings, 1998; Provan & Sebastian, 1998). They alleviate some of the tension between budgetary and policy goals, and reduce the tendency of “policy-making by budget” (Organization for Economic Cooperation and Development, 2000). Decision-makers work with colleagues, not only to address their joint policy goals, but also to save costs within their departments and across the system as a whole. Researchers (Browne, Byrne, Roberts, Gafni, & Whittaker, 2001; Browne, Roberts, Byrne, Gafni, Weir, & Majumdar, 2001; Organization for Economic Cooperation and Development, 2000) have found that collaboration and integration of services for vulnerable populations are more effective, efficient, and less costly than narrowly

focused initiatives. Concerted efforts are required to create collaboration across sectors with the goal of integrating services for families of children with disabilities.

Health Literacy

Health literacy problems have increased as health professionals and health care system providers expect individual patients to assume more responsibility for their care at a time when the health system is increasingly fragmented, complex, and specialized (Parker, 2000). Typical approaches to delivery of service to families of children with disabilities focus on teaching information about needs and services. This is basic or functional health literacy (Boswell, Cannon, Aung, & Eldridge, 2004; Kickbusch, 2001; Parker, 2000; Ratzan, 2001; Tappe & Galer-Unti, 2001). Indeed, parents who receive information about their child's disability are better adjusted emotionally and manage to access more services for their child (Pain, 1999). However, a complete skill-set in health literacy must include more than basic knowledge skills (reading and writing) (Nutbeam, 2000).

Communicative or interactive literacy (Nutbeam, 2000) includes knowledge of cooperative communication approaches and problem solving (Drummond, Fleming, McDonald, & Kysela, 2005). This level of health literacy can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances. Critical literacy (Nutbeam, 2000) includes even more advanced cognitive skills like cooperative advocacy and mediation. The ability to critically analyze and use information to exert greater control over life events and situations is developed. These three levels of health literacy (functional, interactive, and critical) progressively allow for increased autonomy and individual empowerment. Individuals with only skills in reading and writing will have less developed skills to act upon information received. Using interactive and critical literacy skills to work effectively with service providers can be very empowering for parents (Fine & Gardner, 1994). Empowered families experience less stress (McCubbin & McCubbin, 1988) and are able to maneuver within the system to shorten waiting times for services for their children (Feldman, Champagne, Korner-Bitensky, & Meshefedijians, 2002).

Over the years, the writers have developed and tested approaches that address both interactive and critical literacy. These include family-centered assessment and planning approach (McDonald et al., 1997), and cooperative family learning (Drummond et al., 2005). What has been missing for the client who has access to these approaches is service collaboration directed at service integration for families of children with disabilities. To combine the inter-sectoral collaboration that focuses on service integration with health literacy approaches, we propose the use of supportive brokerage and active outreach. These approaches include the following practices: *family-centered* assessment and planning that focus on strengths as well as needs; *relevant information* including community resource referral with names of responsive contact persons; *skill training* including cooperative communication, problem solving, mediating, and advocacy; *consistent follow-up* with families to ensure that child and family goals are met; and *collaborative relationships* between the community-based services linked-to by families.

Parents believe that, with coordination, improved consistency, a family-centered approach and access to information, they could focus their time and energy on looking after their child with a disability and minimize the effect of having a child with a disability on the rest of the family (Ray, 2002). While the principles of family-centered care have been well documented in the literature (Garwick et al., 1998), families reported that these were exactly the principles they found lacking in the systems (Ray, 2002). Family-centered service (FCS) emphasizes a partnership between parents and service providers, focuses on the family's role in decision-making about their child, and recognizes parents as experts on their child's needs (Rosenbaum, King, Law, King, & Evans, 1998). To deliver FCS, service providers must collaborate with families about assessment and treatment of children, listen to families and identify family needs, provide individualized services, encourage participation of all family members, and provide clear, ongoing communication with families (Rosenbaum et al., 1998). The goals and needs of families change over time and service providers need to be responsive to these changes. Thus, family-centered services associated with supportive brokerage and active outreach are not static one-time service initiatives, but are ongoing processes between service providers and families as equal partners.

References

- Abidin, R. R. (1995). *Parenting Stress Index (3rd ed)*. Professional Manual. Charlottesville, VA: Pediatric Psychology Press.
- Bailey, D. B., McWilliam, R. A., Darkes, L. A., Hebbler, K., Simeonsson, R. J., Spiker, D., et al. (1998). Family outcomes in early intervention: A framework for program evaluation and efficacy research. *Exceptional Children, 64*, 313-328.
- Bayley, N. (1993). *Manual for the Bayley Scales of Infant Development (2nd ed.)*. San Antonio, TX: The Psychological Corporation.
- Beresford, B. A. (1995). *Expert opinions: A survey of parents caring for a severely disabled child*. Bristol: Policy Press.
- Betz, C. L., Baer, M. T., Poulsen, M., Vahanvaty, U., & Bare, M. (2004). Secondary analysis of primary and preventive services accessed and perceived service barriers by children with developmental disabilities and their families. *Issues in Comprehensive Pediatric Nursing, 27*, 83-106.
- Boswell, C., Cannon, S., Aung, K., & Eldridge, J. (2004). An application of health literacy research. *Applied Nursing Research, 17*, 61-64.
- Bronfenbrenner, U. (1979) Contexts of child rearing: Problems and prospects. *American Psychologist, 34*, 844-850.
- Brown, I. (1999). Embracing quality of life in times of spending restraint. *Journal of Intellectual and Developmental Disabilities, 24*, 299-308.
- Brown, I., Anand, S., Fung, W. L. A., Isaacs, B., & Baum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities, 15*, 207-230.
- Browne, G., Byrne, C., Roberts, J., Gafni, A., Watt, S., Haldane, S., et al. (1999). Benefiting all the beneficiaries of social assistance: The 2-year effects and expense of subsidized versus nonsubsidized quality care and recreation. *National Academies of Practice Forum: Issues in Interdisciplinary Care, 1*, 131-142.
- Browne, G., Byrne, C., Roberts, J., Gafni, A., & Whittaker, S. (2001). When the bough breaks: Provider-initiated comprehensive care is more effective and less expensive for sole-support parents on social assistance. *Social Science & Medicine, 53*, 1697-1710.
- Browne, G., Roberts, J., Byrne, C., Gafni, A., Weir, R., & Majumdar, B. (2001). Translating research. The costs and effects of addressing the needs of vulnerable populations: Results of 10 years of research. *Canadian Journal of Nursing Research, 33*, 65-76.

- Browne, G., & Roberts, J. (2002). *The Integration of Human Services Measure*. Hamilton, ON: McMaster University and Affiliated Health and Social Service Agencies.
- Bruder, M. B. (1997). Toddlers receiving early intervention in childcare centres: A description of service delivery. *Topics in Early Childhood Special Education, 17*, 185-209.
- Campbell, S. K., Gardner, H. G., & Ramakrishnan, V. (1995). Correlates of physicians' decisions to refer children with cerebral palsy for physical therapy. *Developmental Medicine and Child Neurology, 37*, 1062-1074.
- Canadian Association for Community Living. (2003). *A world for all children: Including the rights of children with disabilities in the UN Convention on the Rights of the Child National Plans of Action*. Toronto: Association.
- Canadian Association for Community Living. (n.d.). *Don't exclude our children*. Toronto: Association.
- Canadian Institute for Child Health (2000). *The health of Canada's children: A CICH profile* (3rd ed.). Ottawa, ON: Institute..
- Chisholm, R. (1996). On the meaning of networks. *Group and Organization Management, 21*, 216-236.
- Crnic, K. A., Friedrich, W.N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping and family ecology. *American Journal of Mental Deficiency, 88*, 125-138.
- Diehl, S., Moffitt, K., & Wade, S. (1991). Focus group interviews with parents of children with medically complex needs: An intimate look at their perceptions and feelings. *Children's Health Care, 20*, 170-178.
- Dinnebeil, L. A. (1999). Defining parent education in early intervention. *Topics in Early Childhood Special Education, 19*, 161-165.
- Drummond, J., Fleming, D., McDonald, L., & Kysela, G. (2005). Randomized controlled trial of a family problem-solving intervention. *Clinical Nursing Research, 14*, 57-80.
- Dunst, C. J., & Trivette, C. M. (1997). Early intervention with young at-risk children and their families. In R. T. Ammerman & M. Hersen (Eds.), *Handbook of prevention and treatment with children and adolescents* (pp. 157-177). NY: Wiley & Sons.
- Erickson Warfield, M., Hauser-Cram, P., Wyngaarden Kraus, M., Shonkoff, J. P., & Upshur, C. C. (2000). The effect of early intervention services on maternal well-being. *Early Education and Development, 11*, 499-517.

- Farmer, J. E., Wendi E. M., Clark, M. J., Sherman, A., & Selva, T. J. (2004). Primary care supports for children with chronic health conditions: Identifying and predicting unmet family needs. *Journal of Pediatric Psychology, 29*, 355-367.
- Farmer, J. E., Clark, M. J., & Marien, W. E. (2003). Building systems of care for children with chronic health conditions. *Rehabilitation Psychology, 48*, 242-249.
- Feldman, D. E., Champagne, F., Korner-Bitensky, N., & Meshefedijians, G. (2002). Waiting time for rehabilitation services for children with physical disabilities. *Child: Care, Health & Development, 28*, 351-358.
- Feldman, M. A. (2004). What is early intervention? In M. A. Feldman (Ed.), *Essential reader in early intervention* (pp. 1-4). Oxford: Blackwell.
- Fine, M. J., & Gardner, A. (1994). Collaborative consultation with families of children with special needs: Why bother? *Journal of Educational and Psychological Consultation, 5*, 283-308..
- Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations: Interdisciplinary Journal of Applied Family Studies, 46*, 359-371.
- Fox, H. B., Wicks, L. B., & Newacheck, P. W. (1993). Health maintenance organizations and children with special needs: A suitable match? *American Journal of Diseases in Children, 147*, 546-552.
- Frey, K. S., Greenberg, N. T., & Fewell, R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. *American Journal of Mental Retardation, 94*, 240-249.
- Garwick, A. W., Kohrman, C., Wolman, C., & Blum, R. W. (1998). Families' recommendations for improving services for children with chronic conditions. *Archives of Pediatric and Adolescent Medicine, 152*, 440-448.
- Gavidia-Payne, S., & Stoneman, Z. (1997). Family predictors of maternal and paternal involvement in programs for young children with disabilities. *Child Development, 68*, 701-717.
- Gordon, D., Parker, R., & Loughran, F. (1996). *Children with disabilities in private households: A re-analysis of the OPCS investigation*. Bristol, UK: University of Bristol.
- Gray, B., & Wood, D. (1991). Collaborative alliances: Moving from practice to theory. *Journal of Applied Behavioral Science, 27*, 3-22.
- Harbin, G. L., McWilliam, R. A., & Gallagher, J. J. (2000). Services for young children with disabilities and their families. In S. J. Meishels &

- J. P. Shonkoff (Eds.), *Handbook of early intervention* (pp. 387-415). Cambridge: Cambridge University Press.
- Harris, E., Wise, M., Hawe, P., Finlay, P., & Nutbeam, D. (1995). *Working together: Intersectoral action for health*. Sydney: Commonwealth Department of Human Health and Services.
- Haveman, M., vanBerkum, G., Reijndewrs, R., & Heller, T. (1997). Differences in service needs, time demands, and caregiving burden among parents of persons with mental retardation across the life cycle. *Family Relations*, 46, 417-425.
- Healey, P. (1997). *Collaborative planning: Shaping places in fragmented societies*. London: Macmillan.
- Huxham, C., & Vangen, S. (2000). Leadership in the shaping and implementation of collaboration agendas: How things happen in a (not quite) joined-up world. *Academy of Management Journal*, 43, 1159-1175.
- Irwin, S. H., & Lero, D. S. (1997). *In our way: Child care barriers to full workforce participation experienced by parents of children with special needs - and potential remedies*. Werck Cove, NS: Breton Books.
- Jennings, E. (1998). Interorganizational coordination, administrative consolidation, and policy performance. *Public Administration Review*, 58, 417-429.
- Kahn, A. J., & Kamerman, S. B. (1992). *Integrating services integration: An overview of initiatives, issues, and possibilities*. New York: National Center for Children in Poverty.
- Kickbusch, I. S. (2001). Health literacy: Addressing the health and education divide. *Health Promotion International*, 16, 289-297.
- Kochanek, T. T., & Buka, S. L. (1998). Patterns of service utilization: Child, maternal, and service provider factors. *Journal of Early Intervention*, 21, 217-231.
- Konrad, E. L. (1996). A multidimensional framework for conceptualizing human services integration initiatives. In J. M. Marquart & E. L. Konrad (Eds.), *Evaluating initiatives to integrate basic human services* (pp. 5-20). San Francisco: Jossey-Bass.
- Lasker, R., Weiss, E., & Miller, R. (2001). Partnership synergy: A practical framework for studying and strengthening the collaborative advantage. *The Milbank Quarterly*, 79, 179-205.
- Mahoney, G., & Bella, J. M. (1998). An examination of the effects of family-centered early intervention on child and family outcomes. *Topics in Early Childhood Special Education*, 18, 83-94.

- McCubbin, H. I., & McCubbin, M. A. (1988). Typologies of resilient families: Emerging roles of social class and ethnicity. *Family Relations, 37*, 247-254.
- McDonald, L., Kysela, G., Drummond, J., Martin, C. A., Wiles, W., & Alexander, J. (1997). Assessment of the clinical utility of a Family Adaptation Model. *Journal of Family Studies, 3*, 47-65.
- National Longitudinal Survey of Children and Youth. (1996). (Data File). Ottawa, ON: Special Survey Division, Statistics Canada.
- National Population Health Survey. (1996-1997). (Data File). Ottawa, ON: Ministry of Industry, Statistics Canada.
- Newacheck, P. W., Strickland, B., Shonkoff, J. P., Perrin, J. M., McPherson, M., McManus, et al. (1998). An epidemiologic profile of children with special health care needs. *Pediatrics, 102*(1Pt.1), 117-23.
- Nutbeam, D. (2000). Health Literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International, 15*, 259-267.
- Organization for Economic Cooperation and Development. (2000). *Strategic governance and policy-making: Building policy coherence*. Paris: The Organization.
- Pain, H. (1999). Coping with a child with disabilities from the parent's perspective: The function of information. *Child: Care, Health & Development, 25*, 299-312.
- Parker, R. (2000). Health Literacy: A challenge for American patients and their health care providers. *Health Promotion International, 15*, 277-283.
- Perrin, E. C., Lewkowicz, C., & Young, M. H. (2000). Shared vision: Concordance among fathers, mothers, and pediatricians about unmet needs of children with chronic health conditions. *Pediatrics, 105*, 277-285.
- Provan, K., & Sebastian, J. (1998). Networks within networks: Service link overlap, organizational cliques, and network effectiveness. *Academy of Management Journal, 41*, 453-459.
- Ratzan, S. C. (2001). Health literacy: Communication for the public good. *Health Promotion International, 16*, 207-214.
- Ray, L. (2005). Categorical service allocation and barriers to care for children with chronic conditions. *Canadian Journal of Nursing Research, 37*, 86-102.
- Ray, L. (2003). The social and political conditions that shape special-needs parenting. *Journal of Family Nursing, 9*, 281-304.
- Ray, L. (2002). Parenting and childhood chronicity: Making visible the invisible work. *Journal of Pediatric Nursing, 17*, 424-438.

- Renwick, R., Brown, I., & Raphael, D. (1997). *Quality of life in families that have a son or daughter with a developmental disability. Report to the Ontario Ministry of Community and Social Services*. Toronto: University of Toronto, Centre for Health Promotion.
- Richman, N., Stevenson, J., & Graham, P. (1982). *Preschool to School - A Behavioural Study*. London: Academic Press.
- Roehrer Institute. (2000). *Count Us In: A Demographic Overview of Childhood and Disability in Canada*. Toronto: Roehrer Institute.
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centered service: A conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics, 18*, 1-20.
- Sattler, J. M. (2002). *Assessment of Children (4th ed.)*. San Diego: J. M. Sattler.
- Short, R., & Talley, R. (1999). Services integration: An introduction. *Journal of Educational and Psychological Consultation, 10*, 193-200.
- Sloper, P. (1999). Models of service support for parents of disabled children. What we know? What we need to know. *Child: Care, Health & Development, 25*, 85-99.
- Sloper, P., Knussen, C., Turner, S., & Cunningham, C. (1991). Factors related to stress and satisfaction with life in families of children with Down's syndrome. *Journal of Child Psychology and Psychiatry, 32*, 655-676.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health & Development, 18*, 259-282.
- Sloper, P., & Turner, S. (1993). Risk and resistance factors in the adaptation of parents of children with severe physical disability. *Journal of Child Psychology and Psychiatry, 34*, 167-188.
- Swann, W., & Morgan, J. (1992). *Collaborating for comprehensive services for young children and their families - the local interagency coordinating council*. Maryland: Paul H. Brookes.
- Tan, E., Hollander, M., & Hayes, V. E. (2000). Conducting policy research: Children with special needs. *The Canadian Nurse, 96*, 27-33.
- Tappe, M. K., & Galer-Unti, R. A. (2001). Health educators' role in promoting health literacy and advocacy for the 21st century. *Journal of School Health, 71*, 477-482.
- Trivette, C. M., Dunst, C. J., Boyd, K. B., & Hamby, D. W. (1995). Family-oriented program models, helping practices, and parental control appraisals. *Exceptional Children, 62*, 237-248.

- Valentine, F. (2001). *Enabling citizenship: Full inclusion of children with disabilities and their parents*. Ottawa, ON: Canadian Policy Research Networks Inc., accessed at www.cprm.org. March 2005.
- Walker, D., Epstein, S., Taylor, A., Crocker, A., & Tuttle, G. (1989). Perceived needs of families with children who have chronic health conditions. *Children's Health Care, 18*, 196-201.
- Wallander, J. L., & Varni, J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 39*, 29-46.
- Wallander, J. L., Varni, J.W., Babani, L., DeHaan, C.B., Wilcox, K. T., & Bannis, H. T. (1989). The social environment and the adaptation of mothers of physically handicapped children. *Journal of Pediatric Psychology, 14*, 371-387.