



**Perceptions of Social Support Among Canadian-Born and Non-Canadian-Born Parents of Children with Developmental Disabilities**

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# Perceptions of Social Support among Canadian-Born and Non-Canadian-Born Parents of Children with Developmental Disabilities

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*Irene Carter, Wansoo Park & Stephanie Cragg*

## **Introduction**

Raising a family is a very challenging endeavour for those who have children diagnosed with developmental disabilities. The wellbeing of a family is dependent upon factors that include the level of access to social support, the amount of stress they encounter, and their child's specific disability and needs. There are limited studies that document how social supports are being perceived and utilized by non-Canadian born (NCB) parents caring for children with developmental disabilities. This exploratory research intends to better understand how social support is perceived by both Canadian-born (CB) and NCB parents of children with developmental disabilities in the Windsor-Essex community (WEC) of southwestern Ontario. WEC is known for the diversity of its residents who are represented by immigrants (22%), visible minorities (14%), and those who speak a non-official language other than English or French (12%) (Artaman, 2009). Ensemble (2014), a resource agency for families, professionals, and government agencies, advised that in 2012, 912 children with developmental disabilities received support through the Assistance for Children with Severe Disabilities Program (SSAH). This figure, however, does not reflect those parents who self-administer their child's SSAH or become too discouraged to apply due to long waitlists, assuming their child would never reach the top of the list or would receive much less care than thought adequate by parents. Presently, 368 children with developmental disabilities in Windsor-Essex County are on the waitlist for SSAH, including 178 children waiting for needed/approved funding increases, for a total of 546 children and their families waiting for support (Ensemble, 2014). This paper aims to assess parental stress in the hope of high-

lighting similarities and differences in the social support available to CB and NCB parents in this part of southwestern Ontario.

## **What is a Developmental Disability?**

The term "developmental disability" describes a broad range of mental and physical impairments that result in a lack of adaptive behaviour skills. Different terms are used to describe much the same thing, such as, mental retardation in the United States, developmental disability in Canada, and learning disability in the United Kingdom (Brown & Percy, 2007), suggesting that intellectual disability describes an intellectual limitation, and developmental disability describes a lack of ability to do with human development. Children diagnosed with developmental disabilities exhibit functional impairment before adulthood and are likely to require lifetime support. Examples of developmental disabilities include autism, cerebral palsy, Down's syndrome, and muscular dystrophy.

Statistics Canada (2014) explains that some types of disabilities are not identified before age 5. Among school-aged children, developmental delays occur at a rate of 30.7 %, with 37,240 Canadian children displaying developmental and agility-related disabilities, respectively. Developmental disabilities are affected by severity and the number of disabilities. For example, autism severity is viewed on a spectrum from mild to severe with respect to deficits in verbal and non-verbal communication, social awareness, and interactions and imaginative play (Autism Canada, 2009). The presence of multiple disabilities also affect the severity of one's disability. About 1.5 % of all children in Canada are considered to have a severe disability (Statistics Canada, 2014). Thus, the severity of

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overall disability depends not only on the severity of each type of disability, but also the number of disabilities experienced by an individual.

#### **Formal and Informal Social Support**

Social support refers to the assistance an individual receives from others. Support can be emotional, informational, or monetary and it can come from a wide range of sources. The concept of social support is a complex multidimensional construct that includes medical, communal, family, and professional supports. This study explores both formal and informal perceptions of support, considering how the experience of social support impacts the stress experienced by families with disabled children.

Formal support is provided by professionals, such as physicians, social workers, and teachers, and from agencies and service organizations like hospitals and early intervention programs (Glidden & Schoolcraft, 2007). Parents of children with disabilities clearly value the support they receive from doctors, government disability programs, non-profit organizations, respite programs, schools, support groups and other sources (Kelso, French, & Fernandez, 2005). Many parents feel positive about professionals taking their concerns seriously and providing useful information (Moh & Magiati, 2012). Perceptions of professional support also may vary by disability. For instance, the parents of children with cystic fibrosis viewed professionals more positively than did the parents of children with attention deficit disorder (Cronin, 2004). Cross-culturally, there is need for greater professional, governmental, and community support (Wang & Michaels, 2009). Perceived support of, and positive collaboration with, professionals, increases parental satisfaction and leads to reduced stress (Moh & Magiati, 2012).

Parents of children with disabilities who report negative experiences with professionals, agencies, and organizations describe those relationships as superficial and unsupportive (Washington, 2009) or unhelpful (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2006). Formal supports do not necessarily lead to improved parental well-being (White & Hastings, 2004; Duvdevany & Abboud, 2003). In a study by Levine (2009), mothers of children with developmental disabilities

described professionals as being highly critical of their choices and parenting practices. They suggested professionals undermined the mothers' decisions regarding the best interests of their children and were perceived as disempowering. Caregivers who voiced concerns over professionals acting insensitively felt that they were often excluded from their child's treatment (Kelso, French, & Fernandez, 2005).

Accessing support is often a problem when parents lack knowledge of available services (Kelso, French, & Fernandez, 2005). For example, language barriers may hinder access to social support among NCB parents whose native language is not English. Lo (2010) found Chinese parents of children with disabilities in the U.S. were eager for formal supports but found language barriers hindered communications with professionals and agencies, leaving parents feeling vulnerable and unaware of the system and process. Lacking the ability to advocate, some parents felt that they had been taken advantage of when service was denied. Bailey et al. (1999) found in a study of U.S. Latino families that lower English proficiency was correlated with lower Family Support Scale (Dunst, Trivette, & Cross, 1984) scores and higher needs for family and community support.

Cultural norms and values influence the use of professional support. In comparing Chinese and Malay Muslim mothers of children with intellectual disabilities, Ow, Tan, and Goh (2004) observed that social support patterns differed by culture. None of the Malay Muslim mothers had any formal sources of support whereas almost half of the Chinese mothers did. The authors suggest that religious and cultural values, cognitive frameworks, and satisfaction with informal supports may affect formal support needs and service use by different populations.

Similarly, Duvdevany and Abboud (2003) surveyed Arab mothers of children with intellectual disabilities in Northern Israel and found that access to formal supports did not increase participants' willingness to use them. The authors noted that cultural norms and values may prevent families from seeking outside help. For example, some individuals and cultural groups are not ori-

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ented toward verbal, self-exploratory therapies, so formal support in the form of counseling is not always appreciated. Stigma against those with developmental disabilities is also more prevalent in some cultures than in others and can influence willingness to seek help. For example, most Bedouin Arab mothers in Israel who are caregivers of their children will not seek external support due to stigma (Manor-Binyamini, 2011). Turkish parents rated negative societal attitudes toward people with disabilities highest among their daily stressors, which the authors noted could lead to anxiety, isolation, and problems receiving services (Uskun & Gundogar, 2010).

The informal support of family, extended family, friends, and neighbours is often perceived as helpful by parents of children with disabilities and can improve family functioning (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2006). Informal support is suggested to reduce anxiety and stress (White & Hastings, 2004) and can reduce parental depression (Benson & Karlof, 2008).

For most parents of children with disabilities, relationships with immediate and extended family members are important sources of informal support (Levine, 2009). Families can provide social support to both parents and their children, and families are often relied on to meet both immediate and long-term care-giving needs (Levine, 2009). Positive interactions with family members can improve mental health and moderate the negative effects of having a child with a disability, highlighting the importance of encouraging positive familial interactions (Ha, Greenberg, & Seltzer, 2011).

Internal family support is the first-line of defense for parents and their children with developmental disabilities. Gauvin (2006) identifies five major themes of informal support that include advocating within the school system, teaching the child social skills, coping strategies involving stress and behaviour management, becoming educated about the disorder, and finding therapeutic services. Disability self-help groups and organizations have also played a leading role in advocating for change and developing supportive services

in Canada and elsewhere.

In certain non-Western cultures, family members may be the only acceptable sources of support, making strong family relationships extremely important. For Lebanese mothers, the informal support system plays a major role in their well-being (Azar & Badr, 2006). Duvdevany and Aboud (2003) observed that for Arab mothers, informal support was associated with lower marital and economic stress and a greater sense of well-being. Formal support, on the other hand, had no significant association with stress levels, suggesting that, in this culture, seeking support outside of the family may be a source of conflict and shame. Lo (2010) found that the Chinese in the U.S. preferred to be in groups where all the participants were from the same culture and spoke the same language; however, it was very difficult for them to locate disability support groups that were solely for Chinese families.

Informal support assessments should note the importance of social cohesion and family interaction, and its effect on individuals and their relationships. Social cohesion in a family with developmentally disabled children helps them identify possible resources in the community. Cohesive groups are self-maintaining when they experience strong membership attractions and attachments that provide practical aid, emotional support, information, assistance with decision making, and opportunities to broaden existing support networks (Friedkin, 2004). The presence of formal and informal supports is also essential for children who have recently immigrated to a country, especially if they are from a cultural minority, as they can experience significant psychological stressors (Bal & Perzigian, 2013).

Concepts like parental stress, support systems, and even how a person perceives various disabilities may be culturally relative and directly influence how and whether a family looks for social support. Cultural variables include parental beliefs, cultural heritage, religious beliefs and rituals that family members have chosen to practice (Yu-Ren Su, 2006). Culture is known to influence how disability is perceived and understood, which in turn affects people's reactions to and attitudes

toward people with disabilities (Ferguson, 2002). A family with a disabled child may be looked down upon by society, influenced by culture, social biases, and other processes (Dhar, 2009). It is important to note beliefs, attitudes, expectations and parenting practices vary by culture, ethnicity, social class and generation (Luster & Okagaki, 2005), while avoiding the trap of homogenizing a group along cultural lines.

### Stress and Social Support

Parents of children with disabilities experience high levels of parenting stress (Phetrasuwan & Miles, 2009) and more stress than parents of children without disabilities (Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008; Oelofsen & Richardson, 2006). Research demonstrated that these findings regarding stress hold true across various cultures (Manor-Binyamini, 2010; McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2006). Social support can promote wellbeing (Skok, Harvey, & Reddihough, 2006; White & Hastings, 2004), important for parents of children with disabilities since these parents are at a higher risk of developing mental and physical health problems (Benson & Karlof, 2008; Ha, Greenberg, & Seltzer, 2011). In addition, social support is associated with fewer spousal problems (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001), which can have a positive effect on the entire family system. Other benefits of social support include better parenting behavior, such as greater nurturance and less use of punishment (Ceballo & McLoyd, 2002), more positive attitudes toward the child (Shin & Crittenden, 2003), and a more positive parental self-image (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). Social support is important to combat the isolation (Kelso, French, & Fernandez, 2005; Wang & Michaels, 2009) many caregivers face because their limited free time makes it difficult to build nurturing and supportive outside relationships (Azar & Badr, 2006). Sadly, those parents who had succeeded in forming supportive relationships with others in the community often said those relationships later failed because they had little or no time to maintain them (Sivberg, 2002).

Some researchers report that stress is higher in families raising children with developmental and

physical disabilities when compared with families raising children without disabilities (Florian & Findler, 2001). Parenting a child with a disability can result in psychological distress (Benson & Karlof, 2008), which can lead to mental health problems like anxiety and depression (White & Hastings, 2004). Parents' stress scores often fall within the clinical range (Oelofsen & Richardson, 2006) suggesting an increased mental health risk. The good news is that social support can reduce maternal distress regardless of other psychological factors (Horton & Wallander, 2001).

Financial problems can be a major stressor for families of children with disabilities (Raver, Michalek, & Gillespie, 2011). Parents of children with developmental delays report having lower average incomes than parents of children without delays (Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008). This can create stress and uncertainty over how to financially sustain both the family and the disabled child. Stress may also result from time pressures and loss of personal time (Raver, Michalek, & Gillespie, 2011). Many parents report long, exhausting, tightly-scheduled days caring for their child with a disability and a subsequent loss of personal goals and self-identity (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). Parents often cannot take time for their own activities and needs or do not give themselves permission to do so (Phetrasuwan & Miles, 2009). Additionally, stress may be related to the severity of the child's disability (Oelofsen & Richardson, 2006) with more severe disabilities often resulting in higher levels of stress (Plant & Sanders, 2007). The child's age can also be a factor, with younger children creating more stress in certain populations (Delambo, Chung, & Weihe, 2011; Bailey et al., 1999). The above examples indicate intervention should begin early, particularly for parents of young children with developmental disabilities (Delambo, Chung, & Weihe, 2011).

Stress may also be related to the child's characteristics, particularly to his or her inability to become independent (Sivberg, 2002). This effect may be even more pronounced cross-culturally and may be related to cultural values. For example, Delambo, Chung, and Weihe (2011) ob-

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served that while both Asian and non-Asian American parents of children with developmental disabilities experienced above-clinical levels of stress, the Asian American parents experienced greater stress related to their children's problem behaviour and inability to adapt to the environment. The authors speculated that stress may be related to Asian cultural values that hold the parents responsible for the achievement, success, and conformity of their children. When children with disabilities are unable to meet traditional standards and goals, this perceived failure can reflect badly on the parents and create stress. Similarly, Wang, Michaels, and Day (2011) found high levels of perceived stress in the areas of pessimism, child characteristics, and parent and family problems in a sample of Chinese families. Parents were stressed and pessimistic about their children's futures, for reasons ranging from the shortage of services to cultural values and the cultural pressure to keep problems within the family. Another source of stress for parents of children with disabilities who have immigrated to a new country is determining which language their child will learn. Yu (2013) states that multi-lingual parents of children diagnosed on the autism spectrum express concern that speaking more than one language to their child could cause confusion and be a detriment to their skills in either language.

Cultural differences can also influence how disability is perceived and understood. Depending on their individual and cultural lens, people may react with anything from optimism to frustration toward those with disabilities (Cronin, 2004). For some individuals and groups, disability is viewed negatively, leading to increased stress.

For example, Lo (2010) found parents encountered substantial cultural pressure from their extended families and friends who were perceived to be judgmental and unsupportive. Relatives had trouble accepting the child with a disability or distanced themselves from the parents because of it. Reactions included denial of the disability, saying that the child needed more discipline, or citing traditional Chinese thinking that the disability was a deserved punishment for wrong doings in a past life.

Further, in a comparison of American and Korean mothers by Shin and Crittenden (2003), the Korean mothers were more traditional, had more negative attitudes towards their children with disabilities, and perceived more stress than did the American mothers. Attitudes towards the child were direct causes of stress for Korean mothers. Those with more positive attitudes towards their children experienced lower levels of stress. The authors suggested traditional values and negative attitudes toward disability strongly affect familial stress. The shame that Korean parents feel may negate reliance on social support, resulting in severe stress. It is important to consider the values, attitudes, and reactions of various individuals and groups as these may impact the levels of stress experienced and the need for, perception of, and use of supports.

It is essential to note that most of the participants in this study, who functioned as primary caregivers, were mothers. Given this reality, one must also recognize the impact of gender on the stress of caring (Chappell, Gee, McDonald, & Stones, 2003) for a child with autism. Hastings, Kovshoff, Brown, Ward, Epinosa, and Remington (2005) reported that mothers of children with autism reported more stress than fathers. Rice and Prince (2000) and Home (2003) pointed out how social policy often conceals gender issues by using apparently neutral terms such as "caregiver." Home (2003) wrote that the high economic, social, and psychological costs of caring for vulnerable populations go unrecognized where women do 85% of the work (Chappell et al., 2003). It is women who should be acknowledged as having carried the greatest responsibility in the provision of required care to family members (Graham, Swift, & Delaney, 2003; Kendrick, 2001; Rice & Prince, 2000; Wharf & McKenzie, 2004). Current social policy depends on women to care for vulnerable populations (Graham, Swift, & Delaney) at great personal cost. Many provinces returned the sick, elderly, and physically and mentally disabled people to live in communities without transferring the funds saved to assist with this transition (Cossom, 2005). Consequently, women assumed care-giving responsibilities without ade-

quate support.

Gender oppression is evident in participants' complaints of having a constant 24/7 lifestyle laden with stress, restrictions on job availability, absenteeism, long-term disability, strained marital relationships, poor health, and guilt about their parenting (Rice & Prince, 2000). In addition to loss of income and career and personal options, many participants experienced isolation and oppression (Home, 2003) while trying to cope with interventions that were less than they deemed necessary.

Despite these challenges and negative outcomes, raising a child with a disability can also bring benefits, particularly in regard to personal growth (Kelso, French, & Fernandez, 2005). Most parents cope well with disability (Kelso, French, & Fernandez) and find meaning in their experiences (Levine, 2009). They describe their relationships with their children as rewarding, being key sources of happiness and pleasure (Levine, 2009). Horton and Wallander (2001) suggested that neither the child's diagnosis nor the severity of the disability was related to parental distress, implying the family, and not just the child, should be considered regarding intervention (Smith, Oliver, & Innocenti, 2001).

Raver, Michalek, and Gillespie (2011) note that caring for persons with disabilities results in both positive and negative experiences, ranging from increased responsibilities to deeply humbling, enriching, and rewarding moments. Caregivers may feel conflicted at times, but many are optimistic about their experiences and believe that services for persons with disabilities will improve (Carter, 2007, 2009). Improving social support can buffer some negative effects of stress and maintain or improve parents' mental and physical health. There are inconsistent findings on the impact of social supports in helping families to cope; experiences differ considerably across families, likely influenced by individual circumstances (Plant & Sanders, 2007).

Contextual sources of stress and support can directly or indirectly affect parenting by first influencing individual psychological well-being. Parental personality also influences contextual support or stress, which then can shape parenting style (Yu-Ren Su, 2007). For parents with disabled children,

a good method of coping may include a more complete understanding of the disorder which can help relieve parental feelings of guilt and incompetence (Gauvin, 2006). Various programs and systems of support listed in the literature suggest that educational support groups can benefit parents of children diagnosed with Autism and Asperger's syndrome by addressing problems and relieving parental stress. Through these groups, for example, parents can find practical answers about providing services for their children, planning for their future, different communication techniques to try, and how to handle difficult behaviour (Cash, 2006).

Through a comprehensive understanding of social support, developmental disability, and parental stress levels, it is possible to develop a platform of inquiry that can compare perceptions of social support for Canadian-born and Non-Canadian born families. This study aimed to gather data from parents of children with developmental disabilities and to assess available services, the willingness of families to seek them out, and highlight any discrepancies that may exist. Such data will provide opportunities to formulate plans on how to address the family's source of stress and need for social support, based on cultural needs and differences.

### Methodology

Creswell (2014) notes that researchers collect information from individuals who experience the phenomenon, using guidelines that ensure that the researcher understands the social world from the perspective of the participant (Engel & Schutt, 2003). Interview depth is stressed over breadth in a research approach that aims to interpret and understand the participants' experiences (Creswell, 2014). Cultural differences influence how individuals perceive and understand disability, as well as their reactions and attitudes towards those with disabilities. Values and attitudes towards disability that are specific to an individual culture may affect the social support families rely on to raise their children with disabilities. This research aims to address the limited information available on how potential social support is perceived and utilized, and iden-

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tify whether and how these perceptions are different for Canadian-born and non-Canadian born parents of children with disabilities.

A qualitative research design provides a useful way to examine how parents of children with developmental disabilities perceive formal and informal support. The researchers are concerned with understanding the meaning of the parental responses from the participants' perspective. Searching for social meaning in a social context, they use a qualitative approach that provides the greatest learning possibilities and insight into the phenomenon being studied that includes: developing general research questions, selecting relevant site(s) and subjects, collecting relevant data, interpreting data, conceptualizing work, and writing up the findings.

Our main research question for this study was: What are the positive and negative experiences of social support associated with having a child with a developmental disability? The Research Ethics Board of the University of Windsor approved the research (Research Ethics Board Number 09-204) by the main researchers, Irene Carter and Wansoo Park, faculty at the University of Windsor and two student assistants from the University of Windsor. We used purposive sampling to gain access to the parents of 20 children with developmental disabilities, initially by advertising to formal support agencies. The agencies placed a notice in their newsletters or websites advising parents of the research and instructing them to contact the researcher directly to arrange an interview. The letter indicated that the researcher was conducting a study on the parental perceptions of social support and stated that the study was designed to gain insight into how parents perceive social support. Participants signed a guardian/family information and consent form and were instructed they could withdraw from the study at any time, with the option of having their data destroyed, upon request.

In developing a process to contact potential participants and arrange interviews, we also used snowball sampling as a secondary strategy. We asked parents to share the recruitment letter with other parents of children with developmental dis-

abilities who might be potential participants for our study. Based on snowball sampling and cooperation by local agencies working in the area of children disabilities, we succeeded in involving 10 CB parents and 10 NCB parents in 90-minute interviews that included questions listed in Appendix A.

We audio-taped the interviews and analyzed the transcribed data with Atlas.ti (2002-2014). Our team also verified the data by distributing summaries of it to participants and collecting feedback from them about the data. Participants were encouraged to advise the researcher of any discrepancies, differences of opinion about a topic, or any additions to the original interview in their feedback.

This research allowed parents to reflect on the amount and quality of social support that they receive as a parent of a child with a developmental disability. It provided opportunities for parents to tell their story and provide information that may not be known about the state of social support for children with developmental disabilities. It was hoped that voicing helpful possibilities through research about perceived social support may help participants identify strategies to lessen some of the challenges they face.

### Findings

We interviewed 20 participants for this study. They were all the parents of children aged 12 years and younger who had developmental disabilities. Ten of the parents were born in Canada, and ten of the parents were born outside of Canada. Of the CB parents, three were male and seven were female. In the group of parents who had immigrated to Canada, three were male and seven were female. Nine of the CB parents had an income of less than \$40,000 a year, and nine of the NCB parents reported an income of less than \$40,000. All 10 of the CB parents reported that they were fluent in English, and one stated that English was their second language. Nine of the NCB parents reported fluency in English, and nine reported that English was their second language.

The participants revealed information about



their children and the resources they used to care for their children as outlined in Table 1: Demographic Characteristics of Canadian-Born and Non-Canadian Born Parents of Children with Developmental Disabilities. Four of the CB parents reported that their child had been diagnosed with a low degree of disability, while six reported that their child had been diagnosed with a moderate degree of disability. Three of the NCB parents reported that their child had been diagnosed with a low degree of disability, five classified their child as diagnosed with a moderate degree of disability, and two reported that their child had been diagnosed with a high degree of disability. When discussing resources, four of the CB parents reported using family caregivers, five utilized the services of informal supports, and seven received the assistance of formal supports. Three of the NCB parents reported receiving assistance from family caregivers, five used various informal supports, and eight utilized formal supports to care for their children.

In developing themes, responses were not merely matched with the questions in the interview guide. Rather, we coded the data from the transcribed, audiotaped interviews in a line by line process. Snippets of quotations were assigned to codes. Similar codes were combined into a total of 37 categories. The categories are represented in the following list of six themes:

- Theme One: Realizing a Diagnosis
- Theme Two: Promoting Awareness of Needs
- Theme Three: Experiencing Disappointing Social Support
- Theme Four: Appreciating Positive Experiences
- Theme Five: Coping with Isolation and Fear
- Theme Six: Feeling Hopeful

In Theme One: Realizing a Diagnosis, parents discussed receiving their child’s diagnosis and the emotional and cultural situations that influenced

Table 1

*Demographic Characteristics of Canadian Born and Non-Canadian Born Parents of Children with Developmental Disabilities (N = 20)*

Participant Characteristics	Canadian Born Parents (n = 10)	Immigrant Parents (n = 10)
Male (Female)	3(7)	3(7)
Income less than \$40,000	9(1)	9(1)
Fluent in English	10(0)	9(1)
Second Language English	1(9)	10(0)
Child (Autism, Cerebral Palsy, Other)	5(2)(3)3	7(1)(2)
Child Disability (High, Low, Moderate)	0(4)(6)	2(3)(5)
Family Caregivers (Yes, No)	4(6)	3(7)
Informal Support (Yes, No)	5(5)	5(5)
Formal Support (Yes, No)	7(3)	8(2)

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the experience. Eleven of the caregivers interviewed reported having children who were currently under the age of 12 years old. One parent related the difficulties experienced when attempting to obtain a diagnosis for the child, stating:

XXXXX was diagnosed with autism approximately two years ago. The paediatrician knew something was wrong right from the beginning but trying to get help was challenging. The paediatrician had to write letters and make phone calls and it took a while but finally we got put on a waiting list and finally through the psychology assessments he was diagnosed.

Another parent stated, “The first time I noticed [a difference] was when I went back home and I had to compare him with my nieces and nephews.” When discussing the difficulties in obtaining information and assistance regarding their child’s diagnosis, one parent discussed the confusion that can occur while trying to navigate a new culture as well:

There is a lot of immigrants who don’t know how to speak English. Who is going to help them? Sometimes I feel sorry for these parents, and I have seen a lot of these parents when I attended workshops. They don’t know what to do. They don’t know how to go to the Internet to get the proper education or to find somebody to counsel them to tell them what to do...

With respect to cultural perceptions, one parent remarked how cultural perceptions influence their ability to ask for assistance, stating “My family is in Lebanon... We don’t feel we have to ask other people to help because it’s not their son... It’s not their obligation.”

Theme Two: Promoting Awareness of Needs relates to the experiences of parents in obtaining resources for their child and raising awareness of various disability issues. One parent discussed the knowledge that she had gained from their mother,

revealing:

...one of the reasons why I [have] the different supports that I do, part of it was because of my mother, because she had awareness. She knew who to hook me up with...the social workers connected me to all the other organizations...and every single one of these agencies has been just absolutely wonderful.

One parent who had immigrated to Canada stated that she had received support in navigating the often confusing government system “XXXXX [Service Agency] Children’s First supported me with giving me tips about other kinds of support and guided me a little bit with how the system works.” Twelve parents discussed challenging behaviours that they experienced while raising their children. One parent discussed the challenge of obtaining supports to cope with her child’s growing size, commenting:

She’s getting too big for me to get her physically...I just keep thinking ahead to when she’s 16, what am I going to do when she won’t move for me right now. Also with other things, she can be very stubborn. She will go to a spot and cross her arms and she won’t move.

Another challenge mentioned by parents was the stares and comments that they experience from others when they are out in the community with their children. Parents also discussed the need to raise more awareness among community members and government officials, with one parent replying “...a lot more research has to be done. The government needs to put out more money to the families who need it on an individual basis for whatever needs that child has.”

In Theme Three: Experiencing Disappointing Social Support, parents discussed the difficulties they experienced in receiving support to care for their children from various avenues. Seven of the parents who had immigrated to Canada reported experiencing difficulties in the area of family support, with one stating “My parents’ help is a little low because they are far away. They do give

emotional support on the phone.” Parents also reported experiencing difficulty finding friends who are understanding of their situation and willing to provide some assistance. One parent revealed:

It is negative when people do not want to talk about it, so they don't answer their phones. They are not home when you need to talk to them. They say that they don't want to talk about that anymore.

During the interviews two individuals discussed strained family relationships and aging parents as barriers in receiving assistance for their children. Another parent described the difficulties that her parents had in interacting with her grandchildren, stating:

My mother and father don't really know how to act around my kids. They are kind of scared of them because the kids don't communicate with them and they tend to have violent fits at times. So my immediate family is not understanding or very helpful in that sense.

On discussing negative experiences when seeking supports from the community, parents expressed frustration with the lack of community awareness regarding disabilities. One parent stated:

...when I go to go to Wal-Mart or Zellers there's a vehicle taking up a disability parking spot ...I don't think that people are intentionally trying to be rude or trying to be ignorant but I think the bottom line is people don't understand. They don't understand what it's like because they don't live it...

Another parent discussed frustrations with his child's school and its response to bullying, revealing "...the school is not doing what it needs to do when it comes to bullying. He has been bullied twice and I have taken care of that and the school is not doing as much..."

Parents also discussed the difficulties in obtaining funding to assist their children. One parent revealed his frustration by emphasizing:

I believe it's not the fault of the people; it's the fault of the funding...the sup-

port is nice but it's not enough... I want more but I am told I don't qualify for this. There's a waiting list for this, there's a waiting list for that ... it's really frustrating in the system because you don't know what to do!

Other parents echoed this frustration regarding wait lists for programs and services. As one parent said:

The wait lists are the worst part. I find it ridiculous that my children were diagnosed at the age of three and didn't receive IBI therapy until they were 5... during that 20 months there was so much we could have done with the kids because they were only 3-5 and early intervention is the key...

Finally, parents also discussed difficulty in obtaining supports for themselves due to time constraints. One parent revealed, "I never really joined any group, probably because I would say I was too overwhelmed by the whole thing."

A focus was placed on positive experiences obtaining supports in Theme Four: Appreciating Positive Experiences. Thirteen of the parents interviewed said that their families gave them positive support. The interviewees mainly portrayed their families as sources of emotional support, however, a few also described the physical support that their families provided. One parent stated, "We do have a niece who works with the children through respite. She does a great job in helping and so does my wife's cousin." When asked about the support provided by their own parents, the interviewees provided many positive examples. One parent discussed how much assistance his parents provide by declaring:

...my parents and my younger sister have been quite understanding... My parents have always been willing to come over and babysit XXXXX when we needed them to and they were quite happy to do that...

The majority of parents who discussed their spouses and other children reported positive experiences and expressed how much these supports

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assisted them and relieved some of their caregiving burdens. One parent praised her husband, declaring, "He is the only support I have here... without my husband I am pretty sure I would've melted down, I would not know what to do...he's the stronger person." Parents also discussed the supports from friends, with one individual disclosing: "I have a very good friend who has been around since we were young. He has been a great help when I am going through a tough time. He lets me talk and express how I feel." When discussing community supports, many parents spoke positively of the supports and programs that their communities had implemented. One parent discussed the daycare program that his daughter attends, stating:

They have a drop in center and daycare and I bring her there to get social support...it's to get her used to socializing with other children and how to behave... It's a chance for us to interact with other parents and other children...She doesn't stick out. She's just one of them and that makes you feel good.

Another parent discussed how she encouraged her community to become more accessible:

I had to push the town of XXXXX to get a handicap swing installed for my son at the park because I'm tired of the misconception that families with children with disabilities don't want to go out and interact in the community. And we do.

Formal supports were also revealed to be a large source of assistance for parents. One parent discussed the program that their daughter attends at the XXXXX Children's Center, stating:

...they will work on the things that she really needs to work on like her communication. She can't speak yet... They even have a doctor there... they've all been amazing and I'm so thankful...she may not be crawling now if it wasn't for all the support that I have. She may not know as much as she does.

Another parent discussed the assistance that she receives from a support group:

The high functioning support group is once a week. Those people are very nice...they listen to us and they share their experiences too...it was great help because I felt that we were not alone and there were a lot of parents who are struggling and are trying to connect with each other...

Respite workers and other private services were also mentioned as positive forms of assistance, with one parent revealing "We also have family respite. The family respite gives you some time so that so you can hire some workers to stay with the kids if you want to go out or just relax." Two parents also mentioned hiring private speech therapists for their children. As a result of coordinating their child's care and supports, some parents reported that they were not able to maintain employment. One parent disclosed:

I don't have time for work. I have tried really hard but I have decided I couldn't work. I had to quit my job and I had to stay home in order to help him. It was very difficult. I am trying to get back to work because he's getting better. I found out this situation with autism is a 24-hour job."

In Theme Five: Coping with Isolation and Fear, parents discussed their emotions surrounding raising their children and coping with their child's diagnosis. Seven parents reported feeling like they had no resources to assist them with coping. One parent declared:

I don't have nobody here. It's just me, my husband, and my son and the services that I get from outside. I have a friend that I trust. I leave XXXXX with her. This is the only support...I have to do everything by myself...it's very difficult...

Six of the parents who immigrated to Canada reported negative emotions surrounding discover-

ing their child's diagnosis, with one stating:

I carried all my awful feeling[s]. I couldn't think...I'm a bad mother? I was too sad. My child had a disability. I am feeling much better, yes. That's why I could start talking to other people. Before that, I shut out myself completely.

Parents also discussed their fears surrounding raising their children, including the threat of bullying. One parent shared an incident which had occurred to his child: "He was bullied twice at the playground...He had blood in his mouth and around his gum. His teeth and gum were all apart so it took time to heal..." Parents also expressed fears for their children's future as their children finish school and as they continue ageing:

When she's going to be out of school when she's 21, that's going to be really difficult. I'm always looking down the road...I can see respite as she gets older is going to be even more important because I'm going to be old too.

Parents discussed their positive feelings surrounding their child and the future in Theme Six: Feeling Hopeful. One parent gave advice for parents in a similar situation, stating:

Start looking for support with other parents that have the same situation. I was able to talk with someone about what is going on with me. They were really nice because they would take care of my kids.

Spirituality and faith were also a major support for parents, with one parent commenting:

If I didn't have Jesus as my personal saviour, I think that I would be six feet under or in a psychiatric ward because he has brought me through so much. My spirituality is very important because he's the one who keeps me sane. When any problems arise, I can go to him.

Another parent discussed how her church provided support for their child: "People from the church ask how XXXXX is doing. They feel really close to him and they have to ask about him every

day because he's there and they care about him."

In conclusion, both CB and NCB parents reported challenges in obtaining services and funding for their children. Parents who immigrated to Canada reported less immediate family support available to them and also reported more negative feelings upon obtaining their child's diagnosis. Parents also reported fears for their children regarding bullying and their future care. However, many parents reported receiving positive supports from their spouses and families, as well as from the community and various organizations. Overall, parents express positive hope for their children's future and encourage a greater awareness and acceptance of disabilities and accessibility issues.

### Limitations

The research area was restricted to southwestern Ontario. The research does not reflect the views of all CB and NCB parents of children with developmental disabilities. Also, we developed the study themes largely through coding the audio-taped interviews into categories rather than deriving the themes from the participants' answers to the interview guide questions. Using a prepared interview guide with set questions may have limited participant responses. Non-English speaking parents or parents with low English-proficiency were not included in the study. Because non-English speaking parents identified language issues as a barrier to accessing services, even more insight could be gained by interviewing NCB parents whose first language is not English and who have low English proficiency. To better understand cultural factors and their meanings among NCB parents, we recommend more in-depth interviews on the cultural aspects of seeking help for raising children with developmental disabilities.

### Discussion

The interviews of CB and NCB parents of children with disabilities revealed that parents expressed both positive and negative experiences with supports that they received from families, friends, community, and formal supports, and the information obtained from the interviews sup-

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ports current findings in the literature. Parents reported that overall they were coping well with raising a child with a disability, a finding reinforced by Kelso, French, & Fernandez (2005). Many parents expressed how essential support from such areas as medical personnel, government programs, respite programs, and support groups is in assisting them to cope with raising their children and providing for their needs, even though many had trouble learning how to navigate the system to obtain that support, as mentioned by Kelso, French, & Fernandez (2005).

Some of these parents also confirmed the findings of Ow, Tan, and Goh (2004), discussing the differences in support between Canada and the countries where they had lived previously. Parents expressed a cultural influence in their reluctance to seek assistance for their child, and some revealed the misperceptions regarding disabilities that can still occur in their former countries. One parent stated "...my mom and dad and my family does not understand what autism is...in Lebanon, they call it delay in communication, it is a social issue...my parents say he shall outgrow this..." In order to better understand these cultural factors and their meanings among NCB parents, we recommend more in-depth interviews in relation to the cultural aspects of seeking help for raising children with developmental disabilities.

Many participants voiced how they had inequitable experiences related to accessing services and experienced limitations related to social policy and gender. As women have a history of volunteerism and advocacy (Rice & Prince, 2000), as a society, we have a vested interest in supporting women as caregivers by helping women in the manner they deem most important. We need to be cognizant that positive outcomes depend on taking gender issues into consideration. The feminist approach provides another avenue for social workers to address gender issues relevant to the care of children with disabilities. In using a variety of approaches, social workers can assist self-help group members in developing ways to challenge issues and counter oppression at the micro, mezzo, and macro level.

Generally, parents emphasized their dependence on informal supports and their ability to relieve stressors and anxiety, as supported in the literature by White & Hastings (2004). Many parents, particularly those who immigrated to Canada, felt isolated due to the geographical distance of their family members. As mentioned in various studies (Kelso, French, & Fernandez, 2005; Wang & Michaels, 2009), social supports can be extremely effective in reducing the feelings of isolation. One parent revealed, "Well if it had not been for the support of the respite program as well as the government supports that allowed me to have someone come in several times a week, I don't think I would have been able to maintain my sanity or my health..." Parents often experience difficulties and feelings of guilt when they are required to focus on their own needs, as mentioned by Phetrasuwan & Miles (2009) and social supports can serve as a means of reducing the barriers and allowing parents to focus on themselves for a period of time.

The interviews also revealed that there is still a perceived global need for greater supports for parents at all levels of the community, as previously stated by Wang & Michaels (2009). One parent emphasized this by stating "I think globally we need more awareness. These kids are unique. We have to accept them the way they are...if they are aware of those differences they probably tend to be more positive... I think the reason why we got the help we needed is because we educated ourselves. We tried to learn as much as we can to be honest with you."

Financial concerns were also mentioned as a significant challenge to families raising a child with a disability, as stated by Raver, Michalek, and Gillespie (2011). Parents reported a lack of funds to obtain programs and services for their children, and others mentioned the difficulties in navigating the red tape necessary to obtain funding. One parent stated:

It is more costly to have a child with disabilities. You have to go to different places to even be able to get the medical help because the government keeps on cutting back on everything.

These findings indicate that there are a variety of ways in which social workers and social work education can provide assistance to parents raising children with disabilities. As mentioned in the interviews, parents, particularly those new to Canada, often require assistance in navigating the system in order to obtain resources and supports for their children. As one parent noted, "There should be more community services. As soon as your child is diagnosed, there should be a list of facilities you could go to find out what they have available for a child with a disability..." Social workers are in the perfect position to provide education and awareness of these resources to parents. They can also ensure that new Canadians are made aware of reputable agencies and business practices, making it essential for social workers to be aware of community resources and services which offer translations and other multicultural services for new Canadians. Additionally, it is recommended that prospective and future social workers should increase their cultural competency and knowledge of the various cultural issues and perspectives related to disabilities.

Social workers are also in a primary position to increase local and global awareness of disabilities and the various concerns and misperceptions associated with them. At the community level, they can engage in workshops and presentation to raise awareness, as well as petition for changes to help individuals with disabilities navigate their community and achieve their goals. As one parent stated, "I think it would be nice to have a little bit more awareness of how to look at families with children with disabilities...sometimes it is out of ignorance when people walk up to you and ask what's wrong with your child...I think it would be nice to have children more educated as well as parents."

At the national and global level, social workers can further the research and literature in the area of disabilities and can encourage government bodies to place a stronger focus on disability issues and support. Social workers can also provide opportunities such as support groups and information workshops for parents to connect with each other and share their experiences and knowledge. They could also offer free child care at such events to relieve the burden parents face searching for and

paying someone to watch their child while they attend. Finally, social workers can work with parents while their child is at an early age to discuss various options and create a plan of care for the future, which is a major concern of parents.

In conclusion, this study explored the perceived gaps and differences in available social support as noted by immigrant and Canadian-born parents of children with developmental disabilities in the metropolitan Windsor, Ontario, community. The research addressed how social support is perceived by parents of children with developmental disabilities and how these perceptions differed between Canadian and immigrant families. The similarities between Canadian-born and immigrant families included equal participation, income levels, and perceptions of informal support by mothers and fathers who participated in the study. However, immigrant parents reported caring for children with greater needs with less family support and higher levels of formal support. The findings provided greater understanding of perceived and utilized informal and formal support by both Canadian-born and non-Canadian born parents of children with developmental disabilities.

### References

- Artaman, A. (2009). Population report Windsor-Essex County 2009. Retrieved from [http://www.wehealthunit.org/about-us/reports/2009\\_WEC\\_populationreport.pdf](http://www.wehealthunit.org/about-us/reports/2009_WEC_populationreport.pdf).
- ATLAS.ti. (2002-2014). Scientific Software Development. Retrieved from <http://www.atlasti.com/>.
- Azar, M., & Badr, L. K. (2006). The adaptation of mothers of children with intellectual disability in Lebanon. *Journal of Transcultural Nursing*, 17(4), 375-380. doi:10.1177/1043659606291550
- Autism Canada (2009). What are Autism Spectrum Disorders? Retrieved November 12, 2009, from [http://www.autismsocietycanada.ca/understanding\\_autism/what\\_are\\_asds/index\\_e.html](http://www.autismsocietycanada.ca/understanding_autism/what_are_asds/index_e.html).
- Bailey, C. B., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M. E., Rodriguez, P., Vazquez

## Comparing Parental Perceptions of Social Support

---

- Montilla, E., & Skinner, M. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation*, 104(5), 437-451.
- Bal, A., & Perzigian, A.B.T. (2013). Evidence-based interventions for immigrant students experiencing behavioural and academic problems: A systematic review of the literature. *Education and Treatment of Children*, 36(4), 5-28.
- Benson, P. R., & Karlof, K. L. (2008). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39(2), 350-362. doi:10.1007/s10803-008-0632-0
- Brown, I., & Percy, M. (2007). Chapter 1. Overview of developmental and intellectual disabilities. In I. Brown and M. Percy (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (800 pages). Baltimore, Maryland: Brookes Publishing Co.
- Cash, E. (2006). *The Effects of Autism and Asperger's Syndrome: Linking specific behaviours to parental stress*. Dissertation Abstracts International, (c) 99014-145.
- Carter, I. (2007). Experiences of parental advocates in self-help groups for children with autism. Unpublished doctoral dissertation, University of Calgary.
- Carter, I. (2009). A consideration of ambivalence and advocacy in self-help: The case of autism. *International Journal of Self Help and Self Care*, 4(3), 271-285.
- Ceballo, R., & McLoyd, V. C. (2002). Social support and parenting in poor, dangerous neighborhoods. *Child Development*, 73(4), 1310-1321. doi:10.1111/1467-8624.00473
- Chappell, N., Gee, E., McDonald, L., & Stones, M. (2003). *Aging in contemporary Canada*. Toronto: Pearson Education Canada Inc.
- Cossom, J. (2005). Chapter 16: Informal helping and mutual aid. In J. C. Turner & F. J. Turner (Eds.), *Canadian Social Welfare* (pp. 242-260). Toronto: Pearson Education Canada Inc.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Cronin, A. F. (2004). Mothering a child with hidden impairments. *The American Journal of Occupational Therapy*, 58(1), 83-92. doi:10.5014/ajot.58.1.83
- DeLambo, D., Chung, W., & Weihe, H. (2011). Stress and age: A comparison of Asian American and non-Asian American parents of children with developmental disabilities. *Journal of Developmental and Physical Disabilities*, 23(2), 129-141. doi:10.1007/s10882-010-9211-3
- Dhar, R. L. (2009). Living with a developmentally disabled child: Attitude of family members in India. *The Social Science Journal*, 46(4), 738 -755.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52.
- Dunst, C. J., Trivette, C. M., & Cross, A. H. (1984). Family support scale: Reliability and validity. *Journal of Individual, Family and Community Wellness*, 1 (4), 45-52.
- Duvdevany, I., & Abboud, S. (2003). Stress, social support and well-being of Arab mothers of children with intellectual disability who are served by welfare services in northern Israel. *Journal of Intellectual Disability Research*, 47(4-5), 264-272. doi:10.1046/j.1365-2788.2003.00488.x
- Engel, R. J., & Schutt, R. K. (2013). *The practice of research in social work* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Ensemble (2014). *What We Do*. Retrieved from <http://www.ensembleunderstands.com/what-we-do/>
- Ferguson, P.M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education*, 36(3), 124-130. doi: 10.1177/00224669020360030201



- Friedkin, N. (2004). Social cohesion. *Annual Review of Sociology*, 30(1), 409-425.
- Florian, V., & Findler, L. (2001). Mental health and marital adaptation among mothers of children with cerebral palsy. *American Journal of Orthopsychiatry*, 71(3), 358-367.
- Gauvin, J. A. (2006). A proposed group for parents of children with Asperger's Syndrome. *Massachusetts School of Psychology*, 108-120.
- Glidden, L. M., & Schoolcraft, S. A. (2007). Family assessment and support. In J. Jacobson, J. A. Mulick and J. Rojahn (Eds.), *Handbook of intellectual and developmental disabilities* (pp. 391-422). New York: Springer Publishing Co.
- Graham, J. R., Swift, K. J., & Delaney, R. (2003). *Canadian social policy: An introduction* (3rd ed.). Scarborough, ON: Prentice-Hall Canada Inc.
- Ha, J. H., Greenberg, J. S., & Seltzer, M. M. (2011). Parenting a child with a disability: The role of social support for African American parents. *Families in Society*, 92(4), 405-411.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9(4), 377-391.
- Helitzer, D. L., Cunningham-Sabo, L. D., VanLeit, B., & Crowe, T. K. (2002). Perceived changes in self-image and coping strategies of mothers of children with disabilities. *The Occupational Therapy Journal of Research*, 22(1), 25-33.
- Home, A. (2003). Challenging hidden oppression: Mothers caring for children with disabilities. *Critical Social Work*, 3(1).
- Horton, T.V., & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology*, 46(4), 382-399. doi: 10.1037/0090-5550.46.4.382
- Kelso, T., French, D., & Fernandez, M. (2005). Stress and coping in primary caregivers of children with a disability: a qualitative study using the Lazarus and Folkman Process Model of Coping. *Journal of Research in Special Education Needs*, 5(1), 3-10. doi: -3802.2005.00033.x
- Kendrick, M. J. (2001). An independent evaluation of the community based options system of the Nova Scotia Department of Community Services. Unpublished manuscript.
- Levine, K. A. (2009). Against all odds: Resilience in single mothers of children with disabilities. *Social Work in Health Care*, 48(4), 402-419. doi:10.1080/00981380802605781
- Lo, L. (2010). Perceived benefits experienced in support groups for Chinese families of children with disabilities. *Early Child Development and Care*, 180(3), 405-415. doi:10.1080/03004430802002625
- Lopez, V., Clifford, T., Minnes, P., & Ouellette-Kuntz, H. (2008). Parental stress and coping in families of children with and without developmental delays. *Journal on Developmental Disabilities*, 14(2), 99-104.
- Luster, T., & Okagaki, L. (2005). *Parenting: An ecological perspective* (2nd ed.). Mahwah, NJ: Lawrence Erlbaum Associates.
- Manor-Binyamini, I. (2010). Mothers of children with developmental disorders in the Bedouin community in Israel: Family functioning, caregiver burden, and coping abilities. *Journal of Autism and Developmental Disorders*, 41(5), 610-617. doi:10.1007/s10803-010-1080-1
- McConkey, R., Truesdale-Kennedy, M., Chang, M-Y., Jarrah, S., Shukri, R. (2006). The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *International Journal of Nursing Studies*, 45(1), 65-74. doi:10.1016/j.ijnurstu.2006.08.007
- Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. *Autism Spectrum Disorders*, 6(1), 293-303.
- Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, 31(1), 1-12. doi:10.1080/13668250500349367
- Ow, R., Tan, N. T., & Goh, S. (2004). Diverse perceptions of social support: Asian mothers

## Comparing Parental Perceptions of Social Support

---

- of children with intellectual disability. *Families in Society*, 85(2), 214-220.
- Phetrasuwan, S., & Miles, M. S. (2009). Parenting stress in mothers of children with autism spectrum disorders. *Journal for Specialists in Pediatric Nursing*, 14(3), 157-165. doi:10.1111/j.1744-6155.2009.00188.x
- Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51(2), 109-124. doi:10.1111/j.1365-2788.2006.00829.x
- Raver, S. A., Michalek, A. P. M., & Gillespie, A. M. (2011). Stressors and life goals of care-givers of individuals with disabilities. *Journal of Social Work in Disability & Rehabilitation*, 10(2), 115-128. doi:10.1080/1536710X.2011.571536
- Rice, J. J., & Prince, M. J. (2000). *Changing politics of Canadian social policy*. Toronto: University of Toronto Press.
- Shin, J. Y. & Crittenden, K. S. (2003). Well-being of mothers of children with mental retardation: An evaluation of the Double ABCX model in a cross-cultural context. *Asian Journal of Social Psychology*, 6(3), 171-184. doi:10.1046/j.1467-839X.2003.00119.x
- Sivberg, B. (2002). Family system and coping behaviours: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*, 6(4), 397-409. doi:10.1177/1362361302006004006
- Skok, A., Harvey, D., & Reddihough, D. (2006). Perceived stress, perceived social support, and well-being among mothers of school-aged children with cerebral palsy. *Journal of Intellectual and Developmental Disability*, 31(1), 53-57. doi:10.1080/13668250600561929
- Smith, T. B., Oliver, M. N. I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, 71(2), 257-261. doi:10.1037/0002-9432.71.2.257
- Statistics Canada (2014). Profile of disability for children. The 2006 Participation and Activity Limitation Survey: Analytical Report. Retrieved from <http://www.statcan.gc.ca/pub/89-628-x/2007002/4125020-eng.htm>
- Uskun, E., & Gundogar, D. (2010). The levels of stress, depression and anxiety of parents of disabled children in Turkey. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, 32(23), 1917-1927. doi:10.3109/09638281003763804
- Wang, P., & Michaels, C. A. (2009). Chinese families of children with severe disabilities: Family needs and available support. *Research & Practice for Persons with Severe Disabilities*, 34(2), 21-32.
- Wang, P., Michaels, C. A., & Day, M.S. (2011). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of Autism and Developmental Disorders*, 41(6), 783-795. doi:10.1007/s10803-010-1099-3
- Washington, L. (2009). A contextual analysis of caregivers of children with disabilities. *Journal of Human Behavior in the Social Environment*, 19(5), 554-571. doi:10.1080/10911350902983093
- Wharf, B., & McKenzie, B. (2004). *Connecting policy to practice in the human services*. Don Mills, ON: Oxford University Press.
- White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17, 181-190.
- Yu, B. (2013). Issues in bilingualism and heritage language maintenance: Perspectives of minority-language mothers of children with autism spectrum disorders. *American Journal of Speech-Language Pathology*, 22, 10-24. doi: 10.1044/1058-0360(2012/10-0078)
- Yu-Ren Su (2007). *Parenting in a foreign land: The lived experience of Taiwanese immigrants with disabled children in the United States*. Unpublished doctoral dissertation, University of Southern California. (UMI No. 3283548)

**Appendix A: Interview Questions for Canadian Born and Non-Canadian Born  
Parents of Children with Disabilities**

- What are the positive experiences of support available from your family?
- What are the negative experiences of support available from your family?
- What are the positive experiences of support available from your community?
- What are the negative experiences of support available from your community?
- What are your positive experiences with available emotional support?
- What are your negative experiences with available emotional support?
- What are the positive aspects of professional services available to you?
- What are the negative aspects of professional services available to you?