

Stress in Parents of Children with Developmental Disabilities Over Time

Anne M. Ritzema

Department of Educational and Counselling Psychology

McGill University

Montreal, Quebec, Canada

September 2010

A thesis submitted to McGill University in partial fulfilment of the requirements of the degree of Master of Arts in Educational Psychology, School/Applied Child Psychology

© Anne M. Ritzema, 2010

### **Acknowledgements**

This thesis is the culmination of two years of research. Thank you to my family and friends who have encouraged me and without whose support this would not have been possible. Thank you as well to Dr. Sladeczek for her invaluable guidance throughout this project. This study was part of the larger National Early Intervention Research Initiative, led by Dr. Sladeczek. The larger study was funded by grants from the Max Bell Foundation, the Canadian Institute for Health Research, and the Office of Disability Issues. Individual funding from the Social Sciences and Humanities Research Council was also instrumental in allowing me to pursue this undertaking.

## Table of Contents

Abstract .....	5
Résumé .....	6
Introduction .....	7
Literature Review .....	10
Parent Stress .....	10
Parent stress and child well-being .....	11
Stress and depression .....	12
Stress and depression in parents of children with DD .....	15
Child Behaviour .....	16
Child behaviour and parent stress .....	17
Externalizing versus internalizing behaviours .....	19
Behaviour problems and specific disorders .....	20
Problem behaviour and child sex .....	21
Adaptive Functioning .....	22
Care-giving time demands .....	22
Adaptive functioning and child characteristics .....	25
Adaptive functioning and parent stress .....	27
Early Intervention .....	29
History of EI .....	29
EI in Canada .....	31
Child-focused and family-centred EI .....	32
Evaluation of EI programs .....	33
Home- versus centre-based EI .....	34
Parent training EI .....	34
Full- versus part-time EI .....	35
Direct instruction versus mediated learning .....	36
Milieu teaching .....	37
EI programs for specific disabilities .....	37
EI conclusions .....	40
Present Study .....	41
Method .....	43
Participants .....	43
Table 1 .....	44
Table 2 .....	47
Measures .....	48
Parenting Stress Index .....	48
Vineland Adaptive Behavior Scales .....	49
Developmental Behavior Checklist .....	51
Procedure .....	51
Results .....	53
Exploratory Data Analysis .....	53
Hypothesis 1 .....	53
Hypothesis 2 .....	54
Hypothesis 3 .....	54

Hypothesis 4 .....	54
Hypothesis 5 .....	54
Hypothesis 6 .....	55
Summary .....	55
Discussion .....	55
Predictors of Parent Stress at Time 1 .....	56
Change in Problem Behaviours, Adaptive Functioning, and Parent Stress From Time 1 to Time 2 .....	57
Relationship Between Child Characteristics and Parent Stress at Time 2 .....	63
Implications for Practice and Policy .....	64
Limitations and Future Directions .....	65
Contribution to Knowledge .....	69
References .....	69

### Abstract

Stress levels of parents whose children have developmental disabilities (DD) are significantly higher than those of parents with typically developing children. However, few studies have looked at the effects of child characteristics on parent stress over time. The aim of the present study is to assess whether changes in child behaviour problems or adaptive functioning affect parent stress. Using data from the National Early Intervention Research Initiative, predictors and correlates of stress were examined in parents of children with DD who attend early intervention (EI) programs ( $n = 21$ ). Families participated in two rounds of data collection, approximately two and a half years apart. At Time 1 child behaviour problems significantly predicted parent stress ( $\beta = .71$ ,  $t(53) = 7.47$ ,  $p < .0001$ ). Between Time 1 and Time 2 child behaviour problems decreased significantly ( $t(19) = 2.13$ ,  $p < .05$ ), as did parent stress ( $t(19) = 3.58$ ,  $p = .002$ ). At Time 2, child behaviour problems were significantly related with parent stress ( $r(19) = .74$ ,  $p < .0001$ ), and so was child adaptive functioning ( $r(19) = -.53$ ,  $p < .05$ ). The results are discussed in the context of current EI practice and policy in Canada.

### Résumé

Le niveau de stress chez les parents d'enfants ayant une déficience intellectuelle est plus grand que chez les parents d'enfants ayant un développement typique. Néanmoins, peu de recherches ont été menées sur les effets des variables chez les enfants sur le stress qu'éprouvent les parents à la longue. Le but de cette étude est d'évaluer l'impact des changements dans les comportements adaptatifs et problématiques de l'enfant sur le niveau de stress parental. A partir des données du National Early Intervention Research Initiative, cette étude examine les indices du stress chez les parents d'enfants ayant un trouble envahissant du développement qui faisaient partie d'un programme de soins précoces ( $n = 21$ ). Les familles en question ont participé à deux enquêtes à deux années et demi de différence. Lors de l'enquête 1, les comportements problématiques de l'enfant prédisaient considérablement le niveau de stress parental ( $\beta = .71, t(53) = 7.47, p < .0001$ ). Entre l'enquête 1 et l'enquête 2, les comportements problématiques de l'enfant ont diminué considérablement ( $t(19) = 2.13, p < .05$ ), ainsi que le stress parental ( $t(19) = 3.58, p = .002$ ). Lors de l'enquête 2, les comportements problématiques de l'enfant s'avéraient intimement liés au stress parental ( $r(19) = .74, p < .0001$ ) ainsi que les comportements adaptatifs de l'enfant ( $r(19) = -.53, p < .05$ ). Les résultats sont présentés dans le contexte de la pratique des soins précoces et des politiques actuellement en vigueur au Canada.

## Stress in Parents of Children with Developmental Disabilities Over Time

**Introduction**

Raising a child is always stressful, but raising a child with developmental disabilities (DD) can present special challenges for parents. In fact, stress levels of parents whose children have DD are significantly higher than those of parents with typically developing children (e.g., Dyson, 1997; Hassal, Rose, & McDonald, 2005; Minnes, 1998; Solomon, Ono, Timmer, & Goodlin-Jones, 2008). Researchers have shown that the quality of parent-child interactions is central to the development of children (e.g., Hauser-Cram et al., 2001; Martin & Cole, 1993; Minnes, 1998). Parents of children with DD often experience atypical interactions with their children that are due in part to characteristics of their children which are different from those of typically developing children. For instance, children with DD often display a greater number of behaviour problems than typically developing children. Problem behaviours can include aggression, destructiveness, defiance, hyperactivity, sleep disturbances, and anxiety, to name only a few (Feldman, Hancock, Rielly, Minnes, & Cairns, 2000; Jewell, Jordan, Hupp, & Everett, 2009; Keller & Fox, 2009). These problem behaviours can have negative effects on parents due to the stress the behaviours cause and due to the added time management that the behaviours often require (Plant & Sanders, 2007b). The presence of behaviour problems in children with DD has been linked to elevated stress in their parents (e.g., Bromley, Hare, Davison, & Emerson, 2004; Hassal et al., 2005; Hauser-Cram et al., 2001; Pisula, 2007). Furthermore, adaptive behaviour, that is, the collection of conceptual, social, and practical skills that allow individuals to function in their daily lives (American Association on Mental Retardation, 2002), is often limited in children with DD. The added strain of performing more daily living tasks for their children with DD than parents of typically developing children can lead to elevated stress in parents of children with DD (Beckman, 1991; Plant & Sanders, 2007b). For instance, Plant and Sanders (2007b) found that stress in parents of children with DD was related to care-giving tasks for their children, such as

helping and supervising at meal times, cleaning up after their child, bedtime preparation, and helping and supervising toileting, with increased demands correlating with higher stress in parents.

According to Sameroff and Chandler's (1975) transactional model of development, both the environment and the child are malleable, constantly interacting with and being affected by each other. Thus, a transactional conceptualization of child development views children as active agents who engage in organizing and structuring their environments. Therefore, according to Sameroff and Chandler's (1975) model, deviation from typical development is not seen as solely a function of an inborn inability in the child, but rather, as a breakdown in the child-environment transaction that might prevent adaptive development. If parent-child interactions are altered, as is often the case when behaviour difficulties and poor adaptive skills are present, then not only are parents likely to experience high levels of stress, but the bonding process between caregiver and child may be affected. For instance, behaviours and cues such as smiling, vocalizing, and eye contact all promote attachment (Bowlby, 1969/1982; Minnes, 1998). If the child with DD fails to display these behaviours or if the child responds negatively to attempts made by the caregiver to bond with the child, then attachment between the child and the parent may be impeded (Minnes, 1998). Similarly, other researchers have shown that the degree to which the child with DD meets the parents' idealized expectations can affect whether the parents view interactions with their child positively or negatively (Ello & Donovan, 2005). On the other hand, parents' perceptions of their children may not be a case of seeing things in black or white. Some researchers have reported that parents experience both positive and negative experiences simultaneously (Trute, Hiebert-Murphy, & Levine, 2007). Examining parent appraisals and cognitions in mothers of children with either Down syndrome ( $n = 34$ ) or autism/PDD-NOS ( $n = 36$ ), Miodrag and Sladeczek (2009) found that negative appraisals contributed only 0.3% to the overall variance in maternal depression and child diagnosis contributed only 0.1%. Even when parents experience elevated stress due to their children's disabilities, parents continue to have positive feelings toward their

children and, with respect to positive appraisals, do not differ from parents of children without disabilities (e.g., Hastings & Taunt, 2002). Nevertheless, parents' stress is often affected by their interactions with their children, which are affected by the children's behaviour. If allowed to continue, a cycle may develop in which maladaptive child behaviour influences parent affect, in turn affecting parent behaviour, and subsequently negatively impacting parent-child interactions. Such a cycle may lead to reduced quality of life for these families and to an increased burden on our health and education systems in the form of long term care needs for the children with DD who grow up to be adults with DD (Farran, 2000; Grant, 2005; U.S. Department of Education, 2002).

Early intervention (EI) programs focus on education and therapy for families and their young (typically birth to age six) children who are at risk for developmental problems. The goal of such interventions is maintaining or maximizing the child's development in order to minimize delays (e.g., Guralnick, 2001; Guralnick, 2005; Majnemer, 1998), while at the same time assisting parents in their own adaptation to their child (Brinker, Seifer, & Sameroff, 1994) and providing them with support through access to resources and information (e.g., Bailey & Powell, 2005; Guralnick, 2001; Guralnick, 2005; Majnemer & Limperopoulos, 2009; Majnemer & Mazer, 2004; Mazer & Majnemer, 2009). EI is thus an ideal context for addressing the difficulties faced by both parents and their children with DD. However, evaluating the efficacy of EI programs has proven difficult (Guralnick, 2007b). There are a number of different models of EI, each with its own pros and cons (Farran, 2000), and the target population (children with DD) presents as a very heterogeneous group (Burack, 1990), making consensus on best practice difficult to achieve (Farran, 2000). Given this, more research is needed to investigate whether current EI programs are in fact meeting the needs of children with DD and their families. Therefore, the purpose of the present study is to examine whether, within the context of EI, children with DD can improve their behaviour and adaptive skills over a period of approximately two years. A second objective is to evaluate whether positive changes in children (e.g., behaviour and

adaptive skills) are related to reduced parent stress between the initial time of assessment and follow-up.

### **Literature Review**

The goal of this section is to lay out, in detail, the history of and current trends in the literature on stress in parents of children with DD and the relationship between parent stress and child characteristics. The review will begin with the literature on parent stress generally, which will then be followed by a review of the literature on stress in parents of children with DD specifically. Next, the review will examine the literature on child behaviour problems and child adaptive behaviour, while at the same time discussing the literature linking these child characteristics with parent stress. Finally, the review will end with a discussion of the literature on early intervention and its role in promoting positive development in children with DD and their families.

#### **Parent Stress**

The conceptualization of stress underwent a number of transformations over the course of the 20<sup>th</sup> century, with many of the more dramatic shifts occurring from the 1960s on. Of importance here is the shift from a medical physiological conceptualization of stress like the one championed by Seyle (1956) to an interconnected model that accounts for individual differences in the perception and experience of stress (Lazarus & Folkman, 1984). This later model was proposed by Lazarus in 1966 and suggested that stress should be treated as an organizing concept that consists of many variables and processes rather than a single variable. This broader conceptualization would allow for a better understanding of a wider range of phenomena that are involved in both human and animal adaptation (Lazarus & Folkman, 1984). Thus, Lazarus and Folkman (1984) define psychological stress as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p. 19). According to these researchers there are two processes that mediate the person-environment relationship: cognitive

appraisals, which are the questions that ask “why?” and “to what extent?”, and coping, which is the process through which the individual manages the demands of the person-environment relationship when this relationship is appraised as stressful. Our conceptualization of stress has thus come to include the notion that people and groups differ in their sensitivity and vulnerability to events and stimuli and also in their interpretations and reactions to situations in their environment (Lazarus & Folkman, 1984).

Stress is a complex and dynamic process that may change over time (Baxter, Cummins, & Yiolitis, 2000). Since cognitive appraisal plays such a central role in human stress responses (Lazarus & Folkman, 1984), examining the subjective experience of stress is more relevant than examining so-called objective stress, as assessed by an external observer such as a physician. Because individual cognitive processes play such a central role in the experience of stress, perceived stress is more predictive of negative personal outcomes than more objective measures of stress (Baxter et al, 2000).

**Parent stress and child well-being.** The investigation of parent stress is an important component in the study of child well-being. Studies investigating families who are at risk for poor developmental outcomes have shown that when parents are under high levels of stress they show less effective parenting skills (Ostberg, 1998; Secco et al., 2006). In a study of stress in parents of children with developmental disabilities, two types of stress are often examined: child-related stress and parent-related stress. Child-related stress is understood as those characteristics of the child's temperament that are related to the child's difficulties with self-regulation, which the parent finds difficult. These temperamental characteristics can include demandingness, lack of adaptability, and negative mood, as well as the child's low social acceptability (Hauser-Cram et al., 2001). Parent-related stress includes those aspects of parenting that result in troubled emotional equilibrium in the parent. For example, parent-related stress may involve social isolation, depression, strained relationships, and poor health (Hauser-Cram et al., 2001).

Parent stress has been associated with less effective parenting skills. For instance, in a sample of parents ( $n = 140$ ) who sought help for their young (2- to 45-month old) children at a specialist clinic, Ostberg (1998) found that mothers in this sample experienced significantly more stress, as measured by the Swedish version of the Parenting Stress Index (PSI) than controls ( $F(1, 1152) = 18.14, p < .0001$ ). Ostberg (1998) also found that there was a significant relationship between parental stress and parents' responsiveness to their children's needs and demands; parents who were rated by both a nurse and a psychologist as having difficulty responding to their child's needs had more elevated stress scores than mothers who did not have difficulty responding to their child's needs (mothers  $r = .49, p < .0001$ , fathers  $r = .36, p < .01$ ). Likewise, in a sample of 61 biologically vulnerable children and their mothers, Secco and her colleagues (Secco et al., 2006) found that mothers who displayed higher competence in caring for their toddlers (aged 14- to 37-months) reported lower stress on the short form of the PSI than did mothers who displayed lower competence in caring for their children, as assessed by the Toddler Care Questionnaire ( $r = -.37, p = .008$ ). In these parent-child dyads, the quality of parent-child interactions was significantly related to parenting stress.

**Stress and depression.** One possible explanation for the relationship between parental stress and less effective parenting skills is the concomitant relationship between stress and depression. In a study that examined the relationship between chronic stress and major depression in a large sample ( $n = 310$ ) of mothers of children with various disabilities (e.g., cystic fibrosis, cerebral palsy, multiple physical handicaps), Bresleau and Davis (1986) found that the rate of depressive symptoms was higher in the sample of mothers of children with disabilities than in the control group ( $n = 357$ ) of mothers of children without disabilities (30.2% versus 16.1%,  $\chi^2 = 18.03, p < .0001$ ). They discovered that while the mothers of children with disabilities were not at increased risk for major depressive disorder, those mothers who did have major depressive disorder reported more depressive episodes than comparison populations with major depressive disorder who did not have children with disabilities ( $16 \pm 29$  versus

6.5  $\pm$  13, respectively,  $t = 2.3$ ,  $p < .02$ ). The authors conclude that chronic stress likely has a role in precipitating depressive symptoms (Bresleau & Davis, 1986). In a more recent study, Abbeduto and his colleagues (Abbeduto et al., 2004) examined depression in mothers of children with DD and found that mothers of children with either Down syndrome ( $n = 39$ ), autism ( $n = 174$ ), or fragile X syndrome ( $n = 22$ ) tended to be more depressed if their family income was low ( $r = -.205$ ,  $p < .01$ ), if they had other children with disabilities in the home ( $r = .148$ ,  $p < .05$ ), if their child displayed more behavioural symptoms as assessed by scores on the Autism Behavior Checklist ( $r = .191$ ,  $p < .01$ ), or if the mother reported fewer problem-focused ( $r = -.134$ ,  $p < .05$ ) and more emotion-focused ( $r = .345$ ,  $p < .001$ ) coping mechanisms. A limitation of this study is the large imbalance in sample sizes between diagnostic categories. The authors state that the inclusion of fragile X syndrome as well as the joint focus on autism and Down syndrome in their study extends existing research that is limited by its focus on just autism or Down syndrome. However, Abbeduto et al. (2004)'s sample consists mainly of children with autism, making comparison between disabilities difficult, if not impossible. This study would be better characterized as an investigation of stress in parents of children with autism in which small comparison groups of Down syndrome and fragile X syndrome were used.

Studies of typically developing children of depressed parents have found that children are at increased risk for a wide range of problems in their psychological functioning when their parents are depressed (Cogill, Caplan, Alexandra, Robson, & Kumar, 1986; Downey & Coyne, 1990; Essex, Klein, Miech, & Smider, 2001). Cogill and colleagues (Cogill et al., 1986) found a significant difference in cognitive performance (assessed at four years of age) between children whose mothers experienced depression within the first year after the child's birth and children whose mothers were not depressed during this time period ( $t = 3.10$ ,  $p < .02$ ,  $n = 94$ ). Twenty-two of the mothers had clinically elevated levels of depression in the first twelve months after their children were born. Examination of the children's McCarthy Scales sub-domain scores at age four revealed that children of depressed mothers

scored significantly lower on the perceptual scale (7.7 points lower,  $p < .001$ ), on the memory scale (4.6 points lower,  $p < .05$ ), and on the motor performance scale (7 points lower,  $p < .005$ ) than children whose mothers were not clinically depressed. It was also found that in families where marital conflict was present during pregnancy or where there was a history of psychiatric problems for the husband, children's cognitive performance at age four was significantly lower than when marital conflict and paternal psychiatric problems were absent ( $t = 2.44, p < .02$  and  $t = 3.02, p < .005$  respectively).

The most recent literature on this issue suggests yet another interpretation of the relationship between parental depression, marital conflict, and child adjustment. For instance, Shelton and Harold (2008) examined two-parent families of 11-13 year old children ( $n = 352$ ) and found that over a one-year period both maternal insecurity and inter-parental conflict were associated with child ratings of parent-child rejection, and parent-child rejection was subsequently related to child adjustment problems. Furthermore, Shelton and Harold (2008) report that both maternal and paternal depressive symptoms at time one and parental insecurity in close relationships at time two (one year later) were significant predictors of increased parental conflict at time two. Increased parental conflict at time two was a significant predictor of both mother- and father-child rejection at time three (one year after time two), which subsequently significantly predicted child externalizing problems ( $b = .006, p < .05$ ) and internalizing problems ( $b = .004, p < .05$ ) at time three. The authors conclude that the relationship between maternal insecurity and mother-child rejection was partially mediated by parental conflict and that parental conflict served as a linking mechanism for paternal insecurity and father-child rejection. In another three-year longitudinal study of two-parent families ( $n = 297$ ), Kouros, Merrilees, and Cummings (2008) found that marital conflict at time one was related to children's elevated emotional insecurity at time two, two years later ( $\beta = .76, p < .01$ ), which in turn was related to higher levels of child-reported internalizing problems ( $\beta = .74, p < .05$ ) at time two. Of interest, Kouros et al. (2008) found that paternal, but not maternal, depression moderated the relationship between marital conflict

and children's emotional insecurity: children whose fathers reported higher levels of depression experienced more emotional insecurity following marital conflict than did children whose parents experienced marital conflict but whose fathers were not depressed.

These studies show that the relationship between parental depression, marital conflict, and child adjustment difficulties is complex. While it may sometimes be the case that parental depression predicts marital conflict (Shelton & Harold, 2008), it does not universally appear to be the case that parental depression only negatively affects child development when it is accompanied by marital discord. Factors such as the timing of children's exposure to either depression or conflict (Essex et al., 2003), the child's gender (Essex et al., 2003; Spence, Najman, Bor, O'Callaghan, & Williams, 2002), or the gender of the depressed parent (Kouros et al., 2008) all appear to affect children's responses to parental depression and conflict and should thus be considered when evaluating the impact of parent and family variables on child adjustment.

**Stress and depression in parents of children with DD.** Parents of children with DD appear to be at risk for both depression and high levels of stress (Abbeduto et al., 2004; Baxter et al., 2000; Breslau & Davis, 1986; Dyson, 1993; Dyson, 1997; Emerson, 2003; Feldman, McDonald, Serbin, Stack, Secco, & Yu, 2007; Glidden & Jobe, 2006; Miodrag & Sladeczek, 2009; Olsson & Hwang, 2001; Richdale, Francis, Gavidia-Payne, & Cotton, 2000; Singer, 2006). In addition, families supporting a child with DD have been found to be significantly more economically disadvantaged when compared with families supporting a child without DD (Emerson, 2003), and socio-economic status has been found to correlate significantly with child outcomes (e.g., Jackson, Choi, & Bentler, 2009; Robins, Dunlap, & Plenis, 1991; Saridjan et al., 2010; Spence et al., 2002; Venetsanou & Kambas, 2010). Finally, the results of a meta-analysis of 18 studies conducted between 1984 and 2003 suggest that the number of mothers of children with DD who score in the clinically significant range for depression appears to have increased by 10% in the past 25 years, whereas a similar increase has

not been found in mothers of typically developing children (Singer, 2006). Kouros et al. (2008) found that 18% of mothers and 16% of fathers ( $n = 297$ ) of typically developing children had clinically elevated stress levels. Conversely, in a sample of mothers of children with either Down syndrome or autism, Miodrag and Sladeczek (2009) found that 60% of mothers experienced clinically significant levels of depression. Given the increased risk for high levels of stress and depression in parents of children with DD and given the association between negative parental affect and poor parenting skills, ameliorating parent well-being in parents of children with DD is imperative. However, studies examining parents' changing stress over time have found that parents' stress increases even when their children attend EI programs (Hauser-Cram et al., 2001). Thus, current intervention practices are not adequately addressing parent stress and more information is needed to guide intervention.

### **Child Behaviour**

One of the earliest identified correlates of stress in parents of children with disabilities is child maladaptive behaviour (e.g., Holroyd & McArthur, 1976; Minnes, 1998). It is often taken for granted that children with DD exhibit more behaviour problems than typically developing children. Thus, there are few studies that examine the prevalence of behaviour problems in children with DD compared with typically functioning children. In the studies that do make this comparison, children with DD have in fact been found to display a greater number of behaviour problems than typically developing children (e.g., Baker et al., 2003; Dekker, Koot, van der Ende, & Verhulst, 2002; Einfeld & Tonge, 1996; Feldman, Hancock, Rielly, Minnes, & Cairns, 2000; Lach et al., 2009; Linna et al., 1999; Lopes, Clifford, Minnes, & Ouellette-Kuntz, 2008). For instance, Dekker et al. (2002) examined behaviour problems in a large sample of children with intellectual disabilities (ID). The sample was divided into two groups based on school placement in the Netherlands: children with ID who attend schools for educable children (IQs between 60 and 80,  $n = 716$ ) and children with ID who attend schools for trainable children (IQs between 30 and 60,  $n = 325$ ). These researchers found that significantly more

children in both of the ID groups of children scored in the clinical range on a measure of maladaptive behaviour (48.1% of the educable children and 51.3% of the trainable children) than the group of children from the general population who served as controls (18.0%). The largest differences between the educable children and the control children were found on measures of social problems (odds ratio = 12.0,  $p < .001$ ), attention problems (odds ratio = 7.1,  $p < .001$ ), and aggressive behaviour (odds ratio = 4.5,  $p < .001$ ). The largest observed differences between the trainable children and the control children were found on measures of social problems (odds ratio = 20.0,  $p < .001$ ), attention problems (odds ratio = 9.1,  $p < .001$ ), withdrawal (odds ratio = 4.8,  $p < .001$ ), and thought problems (odds ratio = 3.3,  $p < .001$ ).

In a similar study, Feldman and colleagues (Feldman et al., 2000) sought to determine the prevalence of behaviour problems in a sample of preschool-aged children with or at risk for DD ( $n = 76$ ). Twenty-five percent of the sample scored in or above the borderline range on the Child Behavior Checklist (CBCL), indicating that they were close to or above the clinical cut-off for problematic behaviours. However, when asked whether their child exhibited behaviour problems, 41% of parents responded in the affirmative. This qualitative information is a strength of this study as it incited the researchers to examine the subscales of the CBCL individually. When the subscales were examined individually, children with DD scored significantly higher than the normative sample on the scales for anxious/depressed ( $t = 52.7$ ,  $p < .05$ ), aggressive behaviour ( $t = 53.5$ ,  $p < .05$ ), sleep problems ( $t = 54.61$ ,  $p < .05$ ), destructive behaviour ( $t = 56.07$ ,  $p < .05$ ), somatic problems ( $t = 56.09$ ,  $p < .05$ ), and withdrawn/isolated ( $t = 56.29$ ,  $p < .05$ ).

**Child behaviour and parent stress.** Compared to the literature on the prevalence of behaviour problems in children with DD, the literature documenting the effects of child behaviour problems on parent well-being is more extensive. Quine and Pahl (1985) conducted a large-scale study ( $n = 200$ ) in which they examined parents' stress and teacher ratings of child behaviour problems. Behaviour

problems included temper tantrums, destructiveness, night-time disturbance, spitting, biting, screaming, wandering, and sexual delinquency. These researchers found that 59% of mothers had malaise scores above the normal range (e.g., scores of 5 and above). There was also a significant association between the severity of the child's behaviour problems and the level of stress reported by the mother (82 of the mothers of children with severe behaviour disorders had a mean malaise score of 7.03). A strength of this study is the fact that the researchers used teacher reports of child behaviour problems, meaning that the parent-reported malaise and teacher-reported behaviour ratings are independent. Therefore, the behaviour ratings are not affected by mother stress at the time of reporting (Quine & Pahl, 1985).

Friedrick, Wilturner, and Cohen (1985) examined stress in three different samples of mothers of children with mental retardation (MR): mothers of children with MR with no motoric or sensory handicaps ( $n = 49$ ), mothers of children with MR with comorbid cerebral palsy ( $n = 41$ ), and mothers of children with Down syndrome ( $n = 30$ ). There was a significant contribution of medical involvement to overall family problems, with mothers of children with higher scores on a measure of medical involvement (problems with speech and language, eating, sleeping, toileting, and physical and motor areas) reporting more stress than mothers who scored lower on this measure of medical involvement ( $F(2, 137) = 23.4, p < .0001, R^2 = .17$ ). Following regression analysis, medical involvement accounted for 2% of the variance of parent and family problems, behaviour problems (conceptualized as the sum of the child's internalizing and externalizing behaviours) accounted for 10% of the variance, and maternal coping resources accounting for a final 36% of the variance in parent and family problems. The authors conclude that the relationship between the variables is likely bidirectional, with parent problems contributing to child behaviour problems and vice versa (Friedrich et al., 1985). This finding of interactive parent-child stress is commensurate with Sameroff and Chandler's (1975) transactional model, and is supported by findings from a review of the literature conducted by Mash and Johnston in 1990. Mash and Johnston (1990) report that in families with a

hyperactive child, stress comes from both parent and child characteristics. In contrast, in families in which there is a physically abusive parent, children do not appear to behave differently from control children, and thus, Mash and Johnston (1990) conclude that the stress experienced in these latter families is not interactive, but unidirectional, stemming from the abusive parent. Looking at stress in parents of children with learning disabilities, Konstantareas and Homatidis (1989) found high correlations for both mothers and fathers between parental ratings of child behaviour problems and parent stress (for mothers  $r = .88$ ,  $p < .001$ , and for fathers  $r = .90$ ,  $p < .001$ ). Similar results have also been found in other studies of children with learning disabilities and attention deficit hyperactivity disorder (62% of parents ( $n = 157$ ) reported that the most stressful event they had experienced in the past year, relating to their child, involved the child's behaviour; McDonald, Couchonnal, & Early, 1996), studies of parents of children with intellectual disabilities ( $r = .488$ ,  $p = .001$ ; Hassall, Rose, & McDonald, 2005), in parents of children with cerebral palsy ( $\beta = -.22$ ; Raina et al., 2005), in parents of children with pervasive developmental disorders ( $F(8, 49) 2.919$ ,  $p < 0.01$ ; Tomanick, Harris, & Hawkins, 2004), and in parents of children with Williams syndrome ( $r = .46$ ,  $p < .05$ ) or Smith-Megenis syndrome ( $r = .55$ ,  $p < .05$ ; Fidler, Hodapp, & Dykens, 2000).

**Externalizing versus internalizing behaviours.** It has been reported that parents may be more stressed by externalizing problems than by internalizing problems in their children ( $F(1, 26) = 8.15$ ,  $p < .01$ ; Konstantareas and Homatidis, 1989). However, these findings are not universally supported. For instance, Margalit and colleagues (Margalit et al., 1989) examined stress in a sample of parents who had children with moderate mental retardation. These researchers found that while mothers were more stressed by externalizing problems, accounting for 38% of the variance in maternal stress, fathers tended to be more stressed by internalizing problems, accounting for 11% of the variance in paternal stress (Margalit et al., 1989). Both studies were published in the same year, however drawing comparisons between the two is difficult given that their samples were not only different sizes, but also

involved different groupings of parents (Konstantareas and Homatidis examined 56 parents of 28 children, whereas Margalit et al. examined 39 different families), they used different measures of parent stress (Konstantareas and Homatidis used the short form of the Self-Concept Inventory whereas Margalit et al. used the Questionnaire on Resources and Stress), and finally, the investigations were conducted in different social and cultural contexts which may not be comparable (Konstantareas and Homatidis drew their sample from Canada, whereas Margalit et al. conducted their research in Israel). Thus, while the results are conflicting, it is difficult to determine which study presents the most accurate picture of the relationship between parent stress and children's externalizing or internalizing behaviours.

**Behaviour problems and specific disorders.** Other researchers have suggested that it is the particular constellation of behaviours that characterize certain disorders which may affect whether it is internalizing or externalizing behaviours which have a more negative affect on parent stress. Fidler et al. (2000) found that neither internalizing nor externalizing behaviours were associated with parent stress in parents of children with Down syndrome ( $n = 20$ ). In parents of children with Williams syndrome ( $n = 20$ ) neither internalizing nor externalizing behaviours were individually associated with parent stress, however, the children's total scores on a measure of behaviour difficulties were significantly related to parent well-being. In parents of children with Smith-Magenis syndrome ( $n = 20$ ), on the other hand, both internalizing ( $r = .58, p < .01$ ) and externalizing ( $r = .53, p < .05$ ) behaviours were significantly related to parent stress (Fidler et al., 2000).

It has been suggested that parents of children with Down syndrome may experience less stress than parents of children with other DD (e.g., Fidler et al., 2000; Hodapp, Ricci, Ly, & Fidler, 2003). Hodapp et al. (2003) found that overall, mothers of children with Down syndrome ( $n = 27$ ) experienced less child-related stress than mothers of children with other developmental disabilities ( $n = 15$ ; e.g., children with no known diagnosis, Prader-Willi syndrome, Williams syndrome, cerebral palsy, and

autism). In their investigation, Hodapp and his colleagues (Hodapp et al., 2003) found that 29.6% of mothers of children with Down syndrome reported clinically elevated levels of child-related stress compared with 73.3% of mothers of children with other DD ( $\chi^2(1, n = 42) = 7.26, p < .01$ ). When the sources of stress in the group of mothers of children with Down syndrome were examined it was found that 32% of the variance in parent stress was accounted for by the maladaptive behaviour construct (Hodapp et al., 2003). Thus, the remaining variance in parent stress was due to other factors unrelated to the child's behaviour. In a study examining stress in parents of children with autism or with Down syndrome, Sanders and Morgan (1997) found that mothers of children with autism reported more parent and family problems ( $M = 9.72, n = 18$ ) than mothers of children with Down syndrome ( $M = 3.29, n = 18$ ), who in turn reported more parent and family problems than did a comparison group of parents with typically developing children ( $M = 2.06, n = 18$ ). These results are similar to those found by Stores, Stores, Fellows, and Buckley (1998), who found that mothers of children with intellectual disabilities (excluding Down syndrome) had higher malaise scores ( $M = 7.28, n = 71$ ) than did mothers of children with Down syndrome ( $M = 5.35, n = 91$ ), who scored higher than mothers of children from the general population ( $M = 4.21, n = 78$ ). Scores of 5 or 6 are considered to be above the normal range and are indicative of stress (Stores et al., 1998).

**Problem behaviour and child sex.** In their study of parents of children with learning disabilities, Konstantareas and Homatidis (1989) found that parents of boys reported greater stress than parents of girls ( $F(1, 26) = 6.12, p < .02, n = 56$ ). Likewise, in a sample of parents of children with DD ( $n = 92$ ), Baker and his colleagues (Baker, Blacher, Crnic, & Edelbrock, 2002) found that boys with DD scored higher than girls with DD on measures of problematic emotional reactivity, aggression, externalizing behaviour, and total problematic behaviour. For both mothers and fathers there was a significant sex effect for negative impact, with parents of boys with DD reporting the highest negative child impact, compared to parents of children without DD and parents of girls with DD (mothers:  $F(1,$

220) = 10.99,  $p = .001$ ; fathers:  $F(1,188) = 6.10$ ,  $p < .05$ ).

### **Adaptive Functioning**

Adaptive functioning, defined by Sparrow, Balla, and Cicchetti (2005), is “the performance of the daily activities required for personal and social sufficiency” (p. 6). Adaptive behaviour is assessed within the individual's environmental context, taking into account age of the individual and cultural and social expectations. Of importance in this definition is the emphasis placed on *performance* of adaptive behaviours, rather than on ability to complete them (Stein, Szumowski, Blondis, & Roizen, 1995; Vig & Jedrysek, 1995). As Sparrow et al. (2005) note, adaptive behaviour is defined by typical performance because even if individuals have the necessary skills to complete a task, if they do not perform those skills when they are needed the individual's adaptive behaviour is inadequate. Several areas of functioning fall under the umbrella of adaptive behaviour, including activities of daily living as well as communication and socialization skills. The current section of this review addresses adaptive behaviour and the deficits that individuals with DD often experience in this area. In addition, the relationship between the ensuing care-taking responsibilities, which often fall on the parents of children with DD, and parent stress will be examined.

**Care-giving time demands.** Activities that are typically included in conceptualizations of “activities of daily living” are eating and drinking, toileting, dressing, bathing, grooming, and health care (Sparrow et al., 2005). In studies that examine the burden of care-taking responsibility in parents of children with disabilities, household chores are often included as an additional care-related burden (Quittner, Opipari, Regoli, Jacobsen, & Eigen, 1992) as are administrative and informational tasks related to the child's disability (Plant & Sanders, 2007b). Children who struggle with the day to day activities cited above require support from a parent or caregiver to accomplish these tasks. For children with disabilities, this struggle is common and is often present across areas of daily living and across the lifespan (Haveman, van Berkum, Reijnders, & Heller, 1997). In a large-scale study conducted across

the Netherlands, Haveman et al. (1997) found that care-giving time demands in a sample of parents of children with mental retardation ( $n = 2,573$ ) were highest for children between birth and nine years of age and averaged 31-60 hours per week. Care-giving time demands in this cross-sectional study were found to decline as children grew older, with the average number of reported care-giving hours ranging from 15-30 in adolescence and adulthood. This study is limited by its use of cross-sectional data, yet it nonetheless provides useful information regarding the additional demands that parents of children with DD face over time. Erickson and Upshur (1989) compared care-taking burden in parents of infants with Down syndrome ( $n = 33$ ), motor impairment ( $n = 43$ ), DD ( $n = 41$ ), and controls with no known disability ( $n = 85$ ). They report that mothers of children with Down syndrome experienced significantly greater care-taking time than controls ( $t = 2.34, p = .023$ ).

When examining time spent on care-demands on weekends, Quittner et al. (1992) found that in addition to spending more time on household and care-giving tasks than control mothers, mothers of children with cystic fibrosis (CF) also spent half as much time as controls engaging in recreational activities (Wilk's Lambda = .73,  $F(2,35) = 6.47, p < .01$ ). In addition, the quality of the recreational activities in which the two groups of mothers engaged were significantly different; mothers of children with CF spent more time in passive leisure activities (e.g., watching TV) and mothers of typically developing children engaged in more active leisure activities (e.g., visiting friends, going out to restaurants and entertainment). These results must be looked at in context. First, Quittner and colleagues had a small sample ( $n = 20$  mothers with children with CF and  $n = 20$  control mothers) and, second, of most relevance to the present investigation, they examined mothers of children with CF, a condition which is better classified as a medical disorder rather than as a developmental disability. Quittner et al.'s (1992) results have nonetheless been found in other populations as well. Leyser, Heinze, and Kapperman (1996) found that parents of visually impaired children engaged in fewer recreational ( $t_{196} = -2.77, p < .006$ ) and intellectual/cultural ( $t_{191} = 2.39, p < .018$ ) activities than

controls. Erickson and Upshur (1989) found that mothers of infants of Down syndrome ( $n = 33$ ) reported less time for themselves than did comparison mothers who had typically developing infants ( $n = 85$ ;  $t = 2.46, p = .018$ ).

In addition to the increased time demands that parents of children with disabilities face due to their children's deficits in adaptive behaviour, these parents must also often deal with complex care demands which may be difficult or physically taxing (Gallagher, Beckman, & Cross, 1983; Plant & Sanders, 2007b). For instance, Plant and Sanders (2007b) investigated stress in parents of preschool-aged children with DD ( $n = 105$ ) and found that the most stressful tasks for mothers were helping and supervising at meal times, cleaning up after their child, bedtime preparation, and helping and supervising toileting. These researchers report strong positive correlations between the level of parent stress associated with care-giving tasks and the difficulty of the care-giving tasks ( $r = .87, n = 101, p < .01$ ). Difficult child behaviour during care-giving tasks was also significantly related to parent reports of stress associated with those tasks ( $r = .66, n = 103, p < .01$ ). In their study of parents of individuals (children and adults) with mental retardation (MR;  $n = 2,573$ ), Haveman et al. (1997) found that the most significant predictors of caregiver burden were the time demands ( $R^2 = .18, p < .001, b = .24, p < .001$ ), behaviour problems ( $R^2 = .27, p < .001, b = .40, p < .001$ ), physical health ( $R^2 = .35, p < .001, b = .19, p < .001$ ), and adaptive skills ( $R^2 = .35, p < .001, b = -.13, p < .001$ ) of the individual with MR. Similarly, Erickson and Upshur (1989) found that parents of infants with DD ( $n = 41$ ) experienced significantly greater child care-taking difficulty with feeding, bathing, and dressing than did comparison mothers of typically developing children ( $n = 85$ ;  $t = 3.20, p = .002$ ). Moreover, Raina and colleagues (Raina et al., 2005) found that care-giving demands were among the most important predictors of caregiver well being in a sample of parents of children with cerebral palsy ( $n = 468$ ). These authors report that decreases in caregiver demands were associated with increases in the physical ( $\beta = .23$ ) and psychological ( $\beta = .12$ ) well-being in parents.

**Adaptive functioning and child characteristics.** Certain child characteristics and disabilities have been linked with adaptive skill deficits in particular areas of functioning. For instance, children with Down syndrome often experience deficits in praxis, which is the planning, execution, and sequencing of movements (Ayres, 1985, as cited in Fidler, Hepburn, Mankin, and Rogers, 2005) and they are known to have impaired motor skills (Fidler, et al., 2005). Combined, these skills deficits can lead to significant impairment in many activities of daily living, including feeding, dressing, and hygiene. Fidler and her colleagues (Fidler et al., 2005) examined whether deficits in praxis were specific to children with Down syndrome, or whether they are more generally associated with DD. They found that children with Down syndrome ( $n = 16$ ) had significantly worse overall motor age equivalents than children with other DD ( $n = 16$ ), achieving lower scores on both gross motor ( $F(2, 47) = 4.98, p < .01$ ) and fine motor ( $F(2, 47) = 3.67, p < .05$ ) tasks. In addition, the group of children with Down syndrome performed significantly worse across all praxis tasks than the group of children with other DD ( $F(7, 18) = 2.95, p < .05$ ). While the sample sizes of the two groups are small, the researchers ensured that the Down syndrome group did not differ significantly from the DD group in terms of chronological age, mental age, or gender, thereby strengthening the conclusions drawn by Fidler et al. (2005). In a longitudinal study of children with DD in early intervention programs ( $n = 183$ ), Hauser-Cram et al. (2001) found that it was children with motor impairment who had less growth in their daily living skills ( $\beta = -.079, p < .05$ ) compared to children with either Down syndrome or other DD, over a seven year period. In addition, children who had higher mastery motivation at age three showed greater growth in the development of daily living skills over time ( $\beta = .030, p < .01$ ).

In a study comparing children with autism ( $n = 46$ ) and children with Asperger's syndrome ( $n = 21$ ), it was found that while both groups of children were below average in their activities of daily living, the two groups nonetheless differed significantly ( $F = 4.61, df = 1,65, p = .035$ ; Szatmari, Archer, Fisman, Streiner, & Wilson, 1995). Using the Vineland Adaptive Behavior Scales (VABS),

which has a mean of 100 and a standard deviation of 15, Szatmari et al. (1995) found that the group of children with autism achieved mean standard scores of 61 on the activities of daily living subscale (a standard score of 61 is equivalent to a percentile rank of .5, and is considered to indicate a profound level of impairment), while the group of children with Asperger's syndrome achieved mean standard scores of 70.8 on the activities of daily living subscale (a standard score of 71 is equivalent to a percentile rank of 3, and is considered to indicate impairment in the borderline range). While there was a significant difference between the autism group and the Asperger's group based on the parent-report VABS, Szatmari and his colleagues (Szatmari et al., 1995) did not find a statistically significant difference between the groups when the teacher-report VABS was used. Therefore, these results might be due to a parent response bias rather than an actual difference.

In a retrospective chart review looking at preschool-aged children with DD Vig and Jedrysek (1995) found a strong positive correlation between adaptive behaviour and intelligence ( $r(485) = .89, p < .001$ ). These researchers also report that the relationship between adaptive behaviour and intelligence was strongest for children with autism ( $r = .79, p = .001$ ), who were deemed to be the most severe disability group, as compared to other children in the sample who had pervasive developmental disorder, language impairment, mental retardation, attention deficit hyperactivity disorder, or cognitive deficit.

Haveman and colleagues (Haveman et al., 1997) found differences in daily living skills between individuals with mild or moderate mental retardation (MR) and individuals with severe MR. For instance, these researchers report that among children in the youngest age group (birth to nine years of age), those with mild or moderate MR required less help than children with severe MR on the following tasks: eating (28% of children with mild or moderate MR versus 78% of children with severe MR), toileting (34% versus 80%), and dressing (55% versus 92%). These group differences weakened in the older age groups, but remained persistent nonetheless. Further, in a study comparing children

with MR ( $n = 112$ ), children with chronic illness ( $n = 73$ ), and children with diagnosed behavioural problems ( $n = 46$ ), Floyd and Gallagher (1997) found that children with MR had the lowest community self-sufficiency scores of the three groups ( $F(4, 192) = 7.48, p < .001$ ) while children with behaviour problems had the lowest personal social responsibility scores ( $F(4, 195) = 9.42, p < .001$ ).

**Adaptive functioning and parent stress.** Deficits in daily living skills in children with DD have repeatedly been associated with parent stress (Beckman, 1991; Floyd & Gallagher, 1997; Hauser-Cram et al., 2001; Haveman et al., 1997; Martin-Doto, 2000; Plant & Sanders, 2007b; Raina et al., 2005; Tomanik, Harris, & Hawkins, 2004; Weiss, Sullivan, & Diamond, 2003). For instance, in their longitudinal study, Hauser-Cram and colleagues (Hauser-Cram et al., 2001) found that mothers of three-year-old children with DD who had higher adaptive behaviour skills reported less child-related stress than mothers of children who had poorer adaptive behaviour ( $\beta = -.771, p < .001$ ). In looking at the stress associated with care demands in parents of children with either MR, chronic illness, or behaviour problems, Floyd and Gallagher (1997) found that parents of children with MR had the highest scores on measures of pessimism (mothers  $F(4, 199) = 7.75, p < .001$ , fathers  $F(4, 120) = 7.80, p < .001$ ), on measures of difficult child characteristics (mothers  $F(4, 199) = 14.09, p < .001$ , fathers  $F(4, 120) = 3.52, p < .01$ ), and on worries about lifespan care (mothers  $F(4, 199) = 11.76, p < .001$ , fathers  $F(4, 120) = 13.01, p < .001$ ) even after child behaviour problems in this group were controlled. Similarly, child adaptive skills were significant predictors of caregiver burden in Haveman et al.'s (1997) study of parents of children with MR ( $R^2 = .35, p < .001, b = -.13, p < .001$ ). In her dissertation examining stress in parents of children with DD, Martin-Doto (2000) found that children's personal self-sufficiency was moderately negatively correlated with greater family stress ( $r(74) = -.53, p < .001$ ). In a sample of children and adults with DD, Weiss et al. (2003) report that personal adjustment significantly predicted maternal child-related stress, accounting for 34% of the variance ( $F(3,49) = 9.70, p < .001$ ). Personal-social responsibility was found to significantly predict maternal parent-

related stress in this sample, accounting for 20% of the variance ( $F(3,46) = 4.35, p < .01$ ). For fathers, both personal-social responsibility and IQ significantly predicted both child-related stress ( $F(3, 35) = 12.45, p < .001$ ) and parent-related stress ( $F(3,35) = 6.89, p < .001$ ; Weiss et al., 2003).

Other researchers have failed to find significant associations between child adaptive behaviour and parent stress. For instance, Blacher et al. (1997) found that only child behaviour problems significantly contributed to parent stress in a sample of Latina mothers of children with MR. All of the mothers in this sample ( $n = 148$ ) were of low SES (with 74% earning an annual family income less than \$20,000) and 42% were single mothers. Due to their disadvantaged status and possibly due to poor English language skills, these mothers may have lacked access to sufficient resources and support to cope with their children's difficulties. In such situations, behavioural problems may have surpassed daily living problems in their significance to these mothers. Due to the nature of this sample, generalization to the population as a whole may be difficult. Hassall et al. (2005) also failed to find significance between adaptive skills deficits in children and stress in their parents. Similar to Blacher et al. (1997), these researchers found that behaviour problems were the only significant predictors of stress in parents of children with intellectual disabilities. However, the authors themselves note that their sample was drawn from a primarily middle-class rural area and the participants may not be representative of the entire population of parents of children with DD. In addition, the sample size was quite small ( $n = 46$ ). Finally, in a study of parents of children with severe intellectual disabilities, Quine and Pahl (1985) found that children's lack of self-help skills alone were not associated with parent stress. However, when dressing and undressing and night-time disturbance were included in self-help skills, the malaise scores of mothers were significantly related with the construct of children's self-help skills. Quine and Pahl (1985) also report that as the number of impairments increased, so did parent malaise (e.g., with two to six additional impairments, mean parent malaise scores rose from 5.04 to 6.03. With seven or ten additional impairments, mean parent malaise scores rose to 7.00. These

associations were all significant at  $p < .05$ ).

### **Early Intervention**

The term early intervention (EI) is used to describe a large number of activities that are designed to enhance the development of young children who are at risk for or who have been diagnosed with a developmental disability. EI, in its best form, begins with a comprehensive assessment of both the child's and the family's strengths and areas of need. Service provision is then tailored to the specific needs of the child and family, with supports and services monitored and reevaluated as the child develops (Ramey & Ramey, 1998). In the context of the current review, the focus is on EI programs for children with DD. EI programs for children with DD typically focus on providing therapy for children birth through age six who have or who are at risk for developmental disabilities. The goal of such interventions is maintaining or maximizing the child's development in order to minimize delays (Majnemer, 1998). These EI programs may also provide education and training for the families of children with DD. In such cases, EI provides multiple forms of support for the family as a whole, including information, suggestions for social interaction strategies, and psychological support. The goal of family-centred EI programs is to foster the positive development of the young child with DD while at the same time assisting parents in their own adaptation to their child (Brinker, Seifer, & Sameroff, 1994; Guralnick, 2001; Guralnick, 2005; Majnemer & Limperopoulos, 2009; Majnemer & Mazer, 2004; Mazer & Majnemer, 2009). According to Guralnick (1997b; 2008) there are several broad principles of EI: EI must centre on the needs of families, be based in local communities, be able to thoroughly and efficiently integrate the contributions of multiple disciplines, and must have the capacity to plan and coordinate supports and services from numerous agencies.

**History of EI.** EI programs for children deemed at-risk for poor developmental outcomes began in the 1960s and 1970s. The primary criterion for determining family disadvantage or high risk was family income, that is, socio-economic status (SES; Ramey & Ramey, 1992). EI programs for low SES

children had as their focus the prevention of negative developmental outcomes and improved future development of at-risk children (Majnemer, 1998; Ramey & Ramey, 1992). The studies between 1977 and 1986 primarily evaluated programs for poor Black children, the focus of which was cognitive remediation or support (Farran, 2000). The setting for these programs was typically centres, and parents were seldom involved in the teaching and remediation process. The short-term outcomes of these initial EI programs were positive, with academic test scores rising immediately (e.g., Barnett, 1995; Farran, 2000). There is less consensus on the long-term benefits. According to Farran (2000), control children caught up to children in the experimental conditions, with the result that both groups were statistically indistinguishable by grade four. On the other hand, Barnett (1995) found sizable long-term effects of EI on school achievement, grade retention, placement in special education, and social adjustment. He notes however, that these improvements were not universal and differed based on the program attended.

In the 1980s there was an expansion of EI programs that extended EI services to children with biological vulnerabilities (e.g., low birth weight) and children with or at risk for DD (Majnemer, 1998). With the advent of the Education of the Handicapped Act Amendments in 1986 (Congress of the U.S., 1986) provisions were put in place for the education of all children within the public education system. Most notably, Part B of the Act created funding incentives for states to provide public education for all eligible three- to five-year-old children with disabilities by 1992. In addition, Part H (now known better as Part C of the Individuals with Disabilities Education Act Amendments; Farran, 2000) offered assistance to states to implement EI services for children from birth through three years of age who had disabilities. However, Part H was not mandatory, simply a guideline (Hawkins, 1986). The assumption behind the provision of EI services to young children with DD is that such an allocation of funds is cost-effective in the long term. In a report to congress in 1985 it was estimated that if intervention services for children with DD began at birth rather than at age six, savings per child could amount to

\$16,000 (Seventh Annual Report to Congress on the Implementation of the Education of the Handicapped Act, as cited by Farran, 2000).

**EI in Canada.** In Canada, unlike the United States, there is no federal act governing EI service delivery provisions or policies (den Heyer & Kienapple, 2005). In an investigation of EI centres in Canada, Karagiannakis, Sladeczek, and Amar (2009) found significant provincial differences in terms of the wait time to obtain an assessment, the number of EI professionals working in their centres, the number of service hours provided per week, the types of services offered, parental satisfaction, program adequacy, and government contributions. Currently, there does not exist a coherent national policy that can assist health authorities in evaluating intervention approaches or in outlining best practices (Sladeczek & Amar, 2005). Consequently, not only are there disparities between provincial policies, but often there is also a lack of consensus among policy makers even within provinces. For instance, in Quebec, policy makers reviewed services to families of children with DD and observed that there is no consensus regarding the types of services needed or best practices to be used for screening, diagnosis, intervention, and evaluation (Cantin & Mottron, 2004; Stuhec & Gisel, 2003). In a national survey of parents of children who attend EI programs across Canada ( $n = 256$ ), parents reported believing that governments (provincial and federal) should do more in terms of providing access to EI services and funding (Ritzema, Saracino, & Sladeczek, 2010). The parents in this study who rated their EI program as more family-centred had higher overall satisfaction with their program ( $r = .552, p < .01$ ), higher satisfaction with their children's outcomes ( $r = .413, p < .01$ ), and higher ratings of program adequacy ( $r = .623, p < .01$ ). Thus, parents' perceptions of their EI programs are related to their perceptions of the effectiveness of those programs. Coupled with parents' reported dissatisfaction with current service provision, these findings highlight the need for greater consensus on EI service provision and policy across Canada.

In an attempt to move toward a national consensus on EI policy in Canada, a working

conference was held in November 2009, with representatives from 10 provinces (Sladeczek & Amar, 2009). All representatives agreed on the urgent need for a national strategy and national guidelines for addressing the EI needs of families of children with DD. It was further agreed that: (a) there is a need for a common language in terms of what EI is and what types of services should fall under an EI mandate, (b) there should be a national accreditation for EI centres to ensure the quality of services provided, (c) there is an urgent need for coordination of government services, since many families are involved with more than one ministry, leaving service delivery fragmented, and (d) there is a need for recruitment and retention of specialized EI personnel. Currently, Sladeczek and Amar (2009) are collaborating with policy makers to combine these recommendations into a brief to be submitted to the Canadian Senate.

**Child-focused and family-centred EI.** Since 1986 there has been an explosion of services for children with DD in the United States (Farran, 2000). In that time a consensus has largely been reached regarding the overarching goals of child-focused EI programs. These goals include maximizing developmental trajectories, promoting social competence and adaptive behaviour, assuring full participation in the least restrictive environment, and preventing or reducing the likelihood of behaviour and health problems (Bailey & Woolery, 1992). Child-focused programs target these goals in particular, through specialized therapies and educational interventions.

Increasingly, there is a trend toward more family-focused EI programs. In these interventions children continue to receive individualized therapies but their family members are also supported, through educational and sometimes training programs. For instance, Gomby and colleagues (Gomby, Lerner, Stevenson, Lewit, & Behrman, 1995) report on family support programs in the United States which serve families with children under three years of age. These programs involve weekly or monthly home visits, classes, or drop-ins, the goal of which is to involve parents in their children's development. Supporting families is, however, a very loosely defined goal. As Bailey and colleagues

(Bailey et al., 1998) note, the field of EI has not yet reached a consensus as to what should be included among the goals for family-centred EI. Initially, parents were viewed as at-home extensions of professionals. The reason given for working with parents was to help them to be better teachers for their children. With the shift to more family-centred care came the notion that all members of the family required support. Thus, a central component of this approach to service is to individualize family services, based on family resources, priorities, and concerns (Bailey & Powell, 2005).

Three themes have emerged in the field of EI (Bailey et al., 1998). First, since families differ in resources, priorities, concerns, and culture, an individualized approach is needed. For instance, some families may need or desire services that go beyond promoting child development (e.g., support groups for parents). Second, a partnership between families and service providers is needed to ensure that families are active in both planning and implementing services. Finally, the third theme is that of families as ultimate decision makers and long-term caregivers of their children. Given this, families must be enabled to become competent advocates for their children (Bailey et al., 1998).

**Evaluation of EI programs.** One issue which arises, particularly given the lack of consensus on the goals of EI, is that of evaluating the effectiveness of EI programs. As Guralnick (1997a) notes, following the Education of the Handicapped Act Amendments of 1986, a number of problems regarding evaluation of EI were encountered. Namely, the inability to gather information and to construct a process that allowed validated approaches to EI for children and families. There was limited empirical information regarding the types of EI that were effective or the methods for adapting programs to fit the unique needs of children and their families (Guralnick, 1997a). While there were many new EI strategies to emerge following 1986, Farran (2000) highlights the fact that it became increasingly difficult to obtain funding for experimental work in EI. Those researchers who reported on their findings in the 1990s were primarily reporting on follow-up studies from the 1970s, which used far more restricted techniques than the EI strategies in vogue at the time (Farran, 2000). Given the

absence of data regarding program efficacy, EI programs appeared to be supported on the basis of ideology rather than on demonstrated outcomes (Siegel, 1996).

***Home- versus centre-based EI.*** One problem with evaluating program efficacy is the large number of different programs that exist, between which it is difficult to draw comparisons. For instance, there is debate as to whether EI services are best provided in the home or in a specialized centre. Researchers conducting studies of home-based programs have reported only moderate gains following intervention. For instance, Diamond and Le Furgy (1992) report a decrease in psychomotor development from pre- to post-test, and Mahoney and Powell (1988) report that while parents' interaction style changed significantly from pre- to post-test, the researchers were unable to draw conclusions regarding positive change in the children.

***Parent training EI.*** A version of home-based intervention, parent training, has shown mixed results. Küçüker (2006) investigated the effects of an eight-month parent training program which sought to reduce parent stress. For two hours per week for the first four weeks parents ( $n = 29$  mothers and  $n = 28$  fathers of  $n = 29$  children) received training on how to implement the program and how to assess their child's development. For the remaining seven months parents implemented the program independently, meeting once per month with other participating parents and professionals. At pre-test, mothers were significantly more depressed than fathers ( $F(1, 28) = 11.38, p < .002$  and  $F(1, 26) = 7.55, p < .01$  respectively). However no statistically significant difference was found between pre- and post-test stress scores for mothers. For fathers, on the child characteristics sub-scale, fathers' stress decreased significantly from pre- to post-test ( $F(1, 27) = 4.83, p < .04$ ).

Mahoney and Powell (1998) conducted an investigation of the effectiveness of the Transactional Intervention Program, the goal of which is to modify patterns of interaction between parents and their children with disabilities. This intervention consisted of weekly home visits conducted for an average of 11 months per family ( $n = 41$ ). No standardized index was used to

compare children's relative developmental status, thus although the authors report that parents' interactions with their children changed significantly from pre- to post-test, this result is less meaningful than it would have been had it been accompanied by information on the effects of the transactional parenting style on child or family functioning. In another study of interaction coaching for parents of children with DD, this one a centre-based model, Seifer, Clark, and Sameroff (1991) investigated an intervention that consisted of two hours of coaching and feedback per week for a period of 10 months. Seifer and his colleagues (Seifer et al., 1991) report only moderate gains for children following the intervention. For instance, only the residualized change scores for mother's ability to stimulate her infant, infant's fussiness, and infant's developmental status were moderately significant (all  $p < .084$ ).

More positive results of parent-training interventions have also been reported. Plant and Sanders (2007a) evaluated the effectiveness of two different types of behavioural parent training: a standard parent training intervention and an enhanced parent training intervention that combined parenting skills and care-giving coping skills. It was reported that both types of interventions were associated with lower levels of negative child behaviour (standard  $t = -13.55$ ,  $p < .05$ , enhanced  $t = -9.96$ ,  $p < .05$ ) and reductions in the number of problematic care-giving tasks (standard  $t = -3.27$ ,  $p < .001$  and enhanced  $t = -4.69$ ,  $p < .001$ ), compared with a wait-list control group. Changes in parenting skills were also associated with both interventions. Parents in the standard condition ( $n = 26$ ) reported significantly higher levels of functional parenting skills ( $t = -.58$ ,  $p < .01$ ) and parenting competence ( $t = 7.40$ ,  $p < .05$ ) compared with the wait-list control group ( $n = 24$ ). Parents in the enhanced condition ( $n = 24$ ) reported significantly higher levels of parenting competence ( $t = 9.78$ ,  $p < .01$ ), but not functional parenting skills, compared to wait-list controls.

**Full- versus part-time EI.** Dihoff and her colleagues (Dihoff et al., 1994) examined the efficacy of full- versus part-time EI for children with DD ( $n = 16$  full-time,  $n = 16$  part-time, and  $n = 14$

controls who qualified for the program but whose parents did not enrol them). They found significant developmental improvements for children in both full- and part-time programs; however, there were differences between the two programs in terms of the length of time after which improvements were observed (e.g., six months versus 12 months) and in terms of the areas of development that showed improvement. For instance, both full- and part-time groups showed improved gross motor skills after six months. However, improvements in expressive and receptive language skills were observed after both the first six months and the second six months for the full-time group, whereas improvements in language skills were not observed for the part-time group until after 12 months. Similar improvements were not found in the control group, thus the authors conclude that the children's improvement in both the full- and part-time programs is not due to maturation.

***Direct instruction versus mediated learning.*** In a comparative investigation of direct instruction versus mediated learning, Dale and colleagues (Dale, Jenkins, Mills, & Cole, 2005) found no significant differences between the two types of intervention in a sample of children with DD ( $n = 205$ ). They did however find an interaction between aptitude and treatment. Using pre-test scores obtained at the start of EI service (between the ages of three and seven) as a measure of aptitude, Dale et al. (2005) found that students who were lower functioning at program entry and who participated in the mediated learning program, as opposed to the direct instruction program, showed more improvements at age 16 than did lower functioning students who participated in the direct instruction program. Conversely, students who were higher functioning at program entry appeared to benefit more from the direct instruction program than the mediated learning program, as assessed by their performance at age 16. Similar results were found in a subsequent follow-up study conducted when the participants were 19 years of age (Jenkins, Dale, Mills, Cole, Pious, & Rork, 2006). Moreover, less severely impaired children appear to progress more in EI programs generally (e.g., Dihoff et al., 1994; Farran, 2000; Fewell & Glick, 1996; Majnemer, 1998).

***Milieu teaching.*** Milieu teaching is a method of intervention in which instruction occurs following the child's lead or interest. Multiple, naturally occurring examples are used to teach simple and elaborated language forms, and the teaching episodes are embedded in ongoing interactions between the teacher and students (Kaiser, Yoder, & Keetz, 1992). Kaiser et al. (1992) conducted a review of the literature on the use of milieu teaching as an EI approach to language instruction for young children with DD. They included 19 studies which were conducted between 1968 and 1990. Overall, the number of children and adolescents receiving milieu teaching in these studies was 134. Kaiser et al. (1992) conclude that in general, none of the studies reviewed provide sufficiently rigorous conditions to allow an evaluation of the effects of milieu teaching on performance outside of the EI context.

***EI programs for specific disabilities.*** Burack and colleagues (Burack, 1990; Burack, Hodapp, & Zigler, 1988; Hodapp & Burack, 2006; Zigler & Hodapp, 1986) have highlighted the importance of moving away from a one-size-fits-all conceptualization of mental retardation in which all individuals with mental retardation are looked at and treated the same way, usually solely on the basis of IQ. Studying the differences within the population of individuals with mental retardation has led to the identification of disorders, such as fragile X syndrome, that were previously lumped into the category of mental retardation (Burack, 1990). Differentiating forms of mental retardation has fostered exploration into interventions specifically tailored to the strengths and weaknesses of the individuals with different disabilities, promoting more positive developmental outcomes for those individuals (Burack, 1990). Following this differentiated model of disability, a number of EI programs have tailored their curricula to specific forms of DD. In what follows, some of those programs are examined, and their effectiveness in various populations is discussed.

Considerable research has been conducted on the effectiveness of EI programs for children with autism. One of the most well-known EI programs was first described by Lovaas in 1987. This seminal

paper describes an intensive behavioural intervention (more than 40 hours per week of individual intervention per child over a period of at least two years) used with 19 children with autism. Their results are compared to those of two control groups of children with autism who did not receive the intensive behavioural intervention, but who instead received either the same behavioural treatment as the children in the experimental group, but only 10 hours per week ( $n = 19$ ), or who received services available in the community ( $n = 21$ ). Lovaas (1987) reports that of the 19 children in the experimental condition, 9 (47%) successfully completed a typical grade one curriculum in a mainstream public school and obtained IQ scores within the average range ( $M = 107$ , range = 94 – 120). What is more, the experimental group gained an average of 30 IQ points over participants in the first control group. While these results are based on a small sample and have received criticism for this and other reasons (e.g., the need for replication, assignment to conditions, and diagnoses of the participants; e.g., Boyd, 1998; Foxx, 1993; Mundy, 1993; Schopler, Short, & Mesibov, 1989), many researchers have reviewed Lovaas' original study and report that although there are limitations with it, as there are with all studies, the results are nonetheless reliable (e.g., Baer, 1993) and they should incite researchers to replicate the original study so that more generalized conclusions might be drawn, with the ultimate goal of improving intervention and outcome for children with autism (e.g., Kazdin, 1993; Mesibov, 1993).

Dawson and Osterling (1997) conducted a comprehensive evaluation of eight EI programs specifically for children with autism. Five of the programs were based on behavioural interventions and/or applied behavioural analysis. The remaining three programs used a play-based approach, an incidental teaching framework, and environmental structuring to facilitate independence and skill acquisition, respectively. The authors note that comparisons between studies are difficult given that the program outcomes are described in different ways. For instance, many researchers reported that children attended mainstream classes following EI, yet they did not consistently report the types or levels of support the children received in those classes. Six of the eight programs did characterize child

outcomes in terms of specific developmental gains, but even those were not comparable as some researchers used IQ scores, others used developmental scores on standardized tests, and still others used observational measures taken in the classroom (Dawson & Osterling, 1997).

An intensive behavioural intervention similar to the one used with children with autism was conducted with three children with Rett's disorder (Smith, Klevstrand, & Lovaas, 1995). Despite thousands of hours of individualized instruction like the children in Lovaas' (1987) study received, all three children with Rett's disorder had very poor outcomes following treatment. The authors note that this difference in responsiveness to treatment based on the etiology of the disorder is critical for treatment planning.

Some interventions have been targeted specifically toward children with Down syndrome. In a review of existing studies of EI for children with Down syndrome, Spiker and Hopmann (1997) report that the majority of researchers have been either cautiously optimistic or outright pessimistic about the effectiveness of EI on overall cognitive development for children with Down syndrome. Several researchers have shown that infants with Down syndrome progress more slowly than infants with other disabilities or delays, and children with Down syndrome tend to show declines over time that children with other disabilities do not exhibit (e.g., Holmes, Britain, Simpson, & Hassanein, 1987; Piper, Gosselin, Gendron, & Mazer, 1986). What is more, very few studies exist that investigate the effects of program intensity for children with Down syndrome (Spiker & Hopmann, 1997), making comparison with the intensive interventions for children with autism impossible. One potentially promising area of intervention for children with Down syndrome is in language and communication. According to Spiker and Hopmann (1997), literature searches reveal a number of articles with conceptual models of language intervention for children with Down syndrome. However, there are not many empirical studies of the effects of implementing specific language stimulation programs (Spiker & Hopmann, 1997).

A further problem that arises in the attempt to evaluate EI programs is the lack of longitudinal studies. The majority of the studies reviewed thus far have looked at change over relatively short periods of time (e.g., one year on average). Not only does such a short time period fail to show the effects of EI across the life span, there is also evidence that assessment during the sensorimotor period of development is an unreliable predictor of later development (Farran, 2000; Farran & Harber, 1989; McCall, Eichorn, Hogarty, Uzgiris, & Schaefer, 1977). Thus, it is not possible to draw any firm conclusions from the majority of studies conducted to date.

**EI conclusions.** The studies reviewed in this section highlight some of the major difficulties in evaluating the efficacy of EI programs for children with DD. Majnemer (1998) concisely summarizes the state of affairs: there appears to be an unsuitability or a lack of sensitivity to existing standardized measures; ethical considerations limit the application of control groups (e.g., no treatment); there is tremendous heterogeneity among children with DD in terms of the degree and type of impairment; the population of children with DD who meet criteria for participation in studies of EI is relatively small; and finally, the use of structured, standardized curriculum is less likely to meet the individual needs of disabled children than less structured, individualized curriculum. According to Guralnick (1997b), specificity is the major theme of what he refers to as “second generation” research into EI, that is, research conducted after 1986. With this in mind, there are three characteristics of children and families which are relevant to the development of specific programs: the severity of the disability, the severity of family risk (e.g., poverty), and the type of child-related risk or disability (Guralnick, 1997b). Thus, the criteria for success of EI need to be understood within the context of who participates and what the goals are, with success defined by the expectations that both the family and the EI practitioners hold for the child and the family (Ramey & Ramey, 1998).

While firm conclusions cannot be drawn, there are nonetheless several general program elements that many researchers believe to be necessary for successful EI outcomes. The first is the

need to involve the whole family (Dawson & Osterling, 1997; Guralnick, 1997b; Ramey & Ramey, 1998). The model of EI that Guralnick (1997b) proposes centres heavily on the importance of providing supports to the family in the form of resources, social supports, and information, all with the aim of reducing the effects of stress on the family. A second common element is an understanding of the importance of highly specialized curriculum that is supported by the teaching environment and that encourages generalization of skills and strategies beyond the EI setting (Dawson & Osterling, 1997; Jenkins et al., 2006). As Farran (2000) concludes, "Providing the right intervention might not be so much finding a single approach to adopt (as in Lovaas) but in determining when in the developmental sequence it is appropriate and facilitating to administer certain forms of intervention" (p. 540).

### **Present Study**

As the above review of the literature has outlined, parents of children with DD often experience high levels of stress. The higher levels of stress have been linked with characteristics of the children with DD, such as behaviour problems and poor adaptive skills. When considering parent stress and its relationship with child characteristics, a transactional model of development can help to guide our understanding of the dynamic processes involved. For instance, parental adaptation to a child's disability is a complex and lifelong process (Hauser-Cram et al., 2001; Poehlmann, Clements, Abbeduto, & Farsad, 2005), one that can change over time as a result of, for example, changes in the parent-child system. These changes can be due to behavioural and adaptive changes in the children, following their participation in EI programs. Thus, the objective of the present study was to clarify the potential relationships between parent stress and child characteristics, to examine whether, within the context of EI, children with DD can improve their behaviour and adaptive skills over a period of approximately two years. The secondary objective was to evaluate whether positive changes in the children (e.g., behaviour and adaptive skills) are related to reduced parent stress between the initial time of assessment and follow-up. If child characteristics are found to predict parent stress then this

will have implications for policy and practice in Canada since traditional models of EI focus either on the children or on the parents, but few take into account the effect that remediating child characteristics can have on parent stress.

The present study addressed three primary sets of questions:

The first set of questions examines the relationship between child characteristics and parent stress (Hypothesis 1, page 53). As previous researchers have shown that both child behaviour problems and low adaptive skills in children with DD are related to stress in the parents, this study sought to determine whether the same relationship exists in this sample of Canadian parents and their children with DD who attend EI programs. It was hypothesized that children's behaviour and adaptive skills would predict parental stress, with parents whose children have fewer behaviour problems and more adaptive skills experiencing less stress than parents whose children have more behaviour problems and fewer adaptive skills.

The second set of questions concerns the change of parent stress and of child characteristics over time (Hypotheses 2 to 4, page 54). The first question explores whether the problem behaviours of children with DD improve over the course of approximately two and a half years (from "Time 1" to "Time 2"). Based on the literature reviewed in the preceding sections, it was hypothesized that children in EI programs would display fewer behaviour problems at Time 2 than at Time 1. The second question was whether children's adaptive skills would increase from Time 1 to Time 2. It was hypothesized that children in EI programs would experience increases in their adaptive skills over time. The third question was whether stress in parents would decrease from Time 1 to Time 2. Based on the literature that shows a relationship between parent stress and child characteristics, it was hypothesized that if children's problem behaviour and adaptive functioning improved over time, then parent stress would go down from Time 1 to Time 2.

The final set of questions (Hypotheses 5 and 6, pages 54-55) explores the relationship between

parent stress and child characteristics at Time 2. The first question asks whether child problem behaviour and parent stress would be related at Time 2. It was hypothesized that if child behaviour problems were associated with parent stress at Time 1 then they would continue to be correlated over time. A second question was whether child adaptive behaviour would be related to parent stress at Time 2. It was hypothesized that if child adaptive skills were related to parent stress at Time 1, then it would be expected that the relationship persist over time.

## **Method**

### **Participants**

The participants were parents (primarily mothers) of children with DD, recruited through three early intervention centres in two large metropolitan cities in Canada. Participants were part of a larger longitudinal National Early Intervention Research Initiative (NEIRI), the primary goal of which is to develop and implement an assessment process to inform public policy on early childhood intervention practice. The ultimate outcome is to develop and implement an action-oriented National blueprint to change current policy and practice in Canadian EI. Eighty-four families returned the consent form agreeing to take part. Full data sets could not be obtained from 39 participants for various reasons (e.g., some children were too young for some of the measures, some parents only agreed to child testing and not to parent testing, some parents completed only some of the measures). This left 56 participating families of children with DD (31 boys and 25 girls) for whom complete data sets were obtained at the first time of testing.

Children ranged in age from 9 months to 10.1 years ( $M = 5.96$ ,  $SD = 2.73$ ). All children entered the study before they turned 10 years of age, but some were not assessed until after they turned 10. Additionally, all children were receiving EI services prior to age 9. All children had a diagnosis of a DD, the most common of which was an autism spectrum disorder (e.g., autism, pervasive developmental delay not otherwise specified, and Asperger's disorder; 39 %), followed by global

developmental delay (19.6%), Down syndrome (12.5%), cerebral palsy (5.3%), Rett's disorder (3.5%), and various other organic, genetic, and disabling conditions (see Table 1 for a complete breakdown of diagnoses). 53 of the respondents were mothers, two were fathers, and one was a paternal aunt. The parents/guardian ranged in age from 23 to 50 years of age ( $M = 38.02$ ,  $SD = 5.97$ ,  $n = 55$ ). Means and standard deviations were calculated based on 55 of the 56 respondents due to nondisclosure of age by one mother. Families were primarily two-parent (91%) and the majority reported having at least a community college education (77%). See Table 1 for complete demographic information.

Table 1

*Child and Parent Demographics at Time 1*

## Demographic categories

Child age in years  $M$  (range)

Site 1	4:6 (0:9 – 9:4)
Site 2	4:9 (2:2 – 9:11)
Site 3	8:6 (6:2 – 10:1)

## Diagnostic group (no.)

Autism/PDD-NOS	18/3
GDD	11
Down syndrome	7
Cerebral palsy	3
Rett's syndrome	2
ADHD	1
Angelman syndrome	1
Asperger syndrome	1
At-risk for DD	1

Table 1 (Continued)

*Child and Parent Demographics at Time 1*

## Demographic categories

Diagnostic group continued (*no.*)

Borderline intellectual disability	1
Communication disorder	1
Hypoxic Ischemic Encephalopathy	1
Low tone	1
Nemaline myopathy	1
Primary carnitine deficiency	1
Tourette's disorder & ADHD	1
Williams syndrome	1

Gender (*no.*)

Males	31
Females	25

Responding parents or guardian (*no.*)

Mothers	53
Fathers	2
Paternal aunt	1

Parent's age (*M, SD*) 38.02 (5.97)\*

Responding parents' level of education (*no. and %*)

High school	6 (10.7%)
Some college/university	2 (3.5%)
College/trade school graduate	15 (26.8%)

Table 1 (Continued)

*Child and Parent Demographics at Time 1*

## Demographic categories

Responding parents' level of education continued (*no. and %*)

University degree	17 (30.4%)
Graduate/professional	11 (19.6%)
Undisclosed	5 (9%)

Parents' marital status (*no. and %*)

Married	51 (91%)
Divorced/Single	3 (5%)
Separated	1 (2%)
Undisclosed	1 (2%)

\* Based on 55 of 56 since one did not disclose age

Participants were contacted again an average of 2.4 years ( $M = 2.37$ ,  $SD = 0.44$ ) after Time 1. Complete data sets were obtained from 21 parents, 19 of whom were mothers and two of whom were fathers (the same two fathers who responded at Time 1). The parents ranged in age from 33 to 52.5 years ( $M = 40.17$ ,  $SD = 5.26$ ). At Time 2, children ranged in age from 3.08 to 12.58 years ( $M = 8.88$ ,  $SD = 3.23$ ). For complete demographics at Time 2, please see Table 2.

Table 2

*Child and Parent Demographics at Time 2*

## Demographic categories

Child age in years (*M*, *range*)

Site 1	5:6 (4:3 – 8:11)
Site 2	7:6 (3:10 – 11:5)
Site 3	11:4 (9:5 – 12:7)

Diagnostic group (*no.*)

Autism/PDD-NOS	6/1
GDD	5
Down syndrome	1
Cerebral palsy	1
Rett's syndrome	1
ADHD	1
Angelman syndrome	1
Borderline intellectual disability	1
Hypoxic Ischemic Encephalopathy	1
Nemaline myopathy	1
Williams syndrome	1

Gender (*no.*)

Males	9
Females	12

Table 2 (Continued)

*Child and Parent Demographics at Time 2*

## Demographic categories

Parents (*no.*)

Mothers	19
---------	----

Fathers	2
---------	---

Parent's age ( <i>M, SD</i> )	40.1 (5.26)
-------------------------------	-------------

Parent's level of education (*no.* and %)

High school	4 (19%)
-------------	---------

College/trade school graduate	3 (14.2%)
-------------------------------	-----------

University degree	7 (33.3%)
-------------------	-----------

Graduate/professional	6 (28.6%)
-----------------------	-----------

Undisclosed	1 (4.8%)
-------------	----------

Parents' marital status (*no.* and %)

Married	19 (90.5%)
---------	------------

Divorced/Single	1 (4.7%)
-----------------	----------

Separated	1 (4.7%)
-----------	----------

**Measures**

**Parenting Stress Index (PSI, long version; Abidin, 1995).** The PSI was used to evaluate stress in the parents of children with DD. The PSI is a standardized self-report questionnaire designed to identify potentially dysfunctional parent-child systems (Abidin, 1995). The PSI consists of 101 likert-scale items for which respondents have the option of choosing strongly agree, agree, not sure, disagree, or strongly disagree. Both child- and parent-related stress are assessed by the PSI, through the Child

Domain and the Parent Domain, respectively. The Child Domain subscale examines actual and perceived stressors related to child characteristics. The Parent Domain subscale examines specific traits of the parent and family context. Together, the Child Domain and Parent Domain create a Total Stress Domain (Abidin, 1995).

For the present study, the Total Stress Domain was used as the dependent variable. Total Stress raw scores of 260 or higher fall in the critical range (80<sup>th</sup> percentile) and are indicative of stress levels that may require psychological intervention (Abidin, 1995).

The PSI has strong internal consistency with coefficient alpha reliability coefficients of .95 for both a normative and a validation sample for the Total Stress Domain. Four different studies assessed the test-retest reliability of the PSI over periods of one month to one year. The correlation coefficients for the Total Stress Domain ranged from .65 to .96. The author notes that these relatively high reliability coefficients provide support for the stability of PSI scores over time (Abidin, 1995).

**Vineland Adaptive Behavior Scales-II, Survey Interview Form (VABS-II; Sparrow, Cicchetti, & Balla, 2005).** The VABS-II was used to assess child adaptive behaviour. The VABS-II is a semi-structured survey interview conducted with parents that assesses adaptive functioning in children (Sparrow, et al., 2005). The VABS-II is composed of four domains: Communication, which is divided into receptive, expressive, and written communication; Daily Living Skills, which includes personal, domestic, and community activities; Socialization, which examines interpersonal relationships, play and leisure time activities, and coping skills; and Motor Skills, which is broken down into fine and gross motor abilities. These four domains make up the Adaptive Behavior Composite Score (Sparrow et al., 2005). The present study examined the Adaptive Behavior Composite to assess adaptive behaviour.

For the purpose of the present study, interviewers used a start point one year below the child's chronological age and worked backwards or forwards depending on responses provided by the parents.

The VABS-II has a basal and a ceiling requirement of four. Therefore, when necessary, interviewers worked backwards until a basal of four consecutive scores of two was attained. Interviewers stopped administering subtest items when a ceiling of four consecutive zeros was reached. The VBAS uses standard scores and has a mean of 100 and a standard deviation of 15. The Adaptive Behavior Composite has a maximum range of 20 to 160, that is, from five standard deviations below the mean to four standard deviations above the mean. Standard scores between 86 and 114 are considered Adequate, scores of 71 to 85 are considered Moderately Low, scores below 70 are considered Low, and scores between 115 and 129 or of 130 and higher are considered Moderately High and High, respectively (Sparrow et al., 2005). Using a sample of parents or caregivers ( $n = 112$ ) of individuals with mental retardation (MR), Sparrow et al. (2005) found that 71.1% of children aged six to 18 with mild MR (IQ range of 50 to 70) scored at or below a standard score of 70 on the VABS-II. Within the same sample, 87.1% of children between six and 18 years of age with moderate MR (IQ range 35 to 49) scored at or below standard scores of 70. Finally, Sparrow et al. (2005) looked at children between six and 18 years of age who had severe to profound MR (IQ under 34) and found that 100% of those children scored at or below a standard score of 70.

Internal consistency of the Adaptive Behavior Composite is very high, with reliability coefficients ranging from .94 to .98 for children birth to 18 years of age. Test-retest reliability of the VABS-II was conducted using sample of 414 respondents, with an interval of 13 to 34 days between interviews. For children aged birth to 21 years of age and taking into account the sex of the child, the test-retest reliability for the VABS-II ranged from 42.2% to 57.8% (Sparrow et al., 2005). The validity of the VABS-II has been rigorously tested using multiple sources of information, including test content, response process, test structure, clinical groups, and relationships to other measures. The authors report that the VABS-II has been demonstrated to be a valid measure for assessing adaptive behaviour in individuals from birth to 90 years of age (Sparrow et al., 2005).

**Developmental Behavior Checklist, Primary Carer Version (DBC-P; Einfeld & Tonge, 1989).** The DBC-P was used to evaluate perceived problem behaviour in the children with DD. The DBC-P is a 96-item parent-report questionnaire that assesses behavioural and emotional difficulties in children, adolescents, and adults with developmental and intellectual disabilities (Einfeld & Tonge, 1989). Child maladaptive behaviour was assessed using the Total Problem Behavior score of the DBC-P. Respondents rate each item with either a 0 (“not true as far as you know”), 1 (“somewhat or sometimes true”), or 2 (“very true or often true”), depending on the respondent’s perception of the degree of presence of a particular behaviour. The authors report that the optimal cut-off point for the DBC-P is 44. A critical value of 44 was found to have a specificity of 85% and a sensitivity of 83% (Einfeld & Tonge, 1989).

Interrater reliability for the DBC-P was calculated using a sample of 42 pairs of mothers and fathers of children with intellectual disabilities and was found to be .80, which is considered high. Test-retest reliability for the DBC-P was evaluated using a sample of 63 pairs of parents, residential care workers, and nurses who completed the questionnaire two weeks apart. Test-retest reliability was .83, which is high. With regards to the DBC-P’s ability to measure change over time, the authors report that, using a reliable change of 1.96, a score of 16.17 indicates change that is not associated with measurement error at the .05 level. Change as measured by the DBC-P was found to be highly correlated with change as rated by experienced clinicians (Einfeld & Tonge, 1989). The validity of the DBC-P was evaluated via a number of studies that examined different aspects of validity such as content validity, construct validity, concurrent validity, criterion group validity, and receiver operating characteristics (Einfeld & Tonge, 1989).

## **Procedure**

The present study was part of the longitudinal National Early Intervention Research Initiative (NEIRI) project tracking the developmental trajectories of families and children with DD receiving EI

services. The primary goal of the NEIRI is to reform Canadian public policy in early childhood intervention so that appropriate and timely services are provided to children with various developmental delays and disabilities and their families.

The study received approval from the Human Subject Research Ethics Board at the University level and from the individual centres and school from which parents were recruited. A letter explaining the purpose, procedures, rights of the participants, and confidentiality, along with a consent form were mailed to families who fit the criteria, inviting them to participate. Parents were informed of the longitudinal nature of the project and the anticipated data collection over the course of several years. A package of questionnaires (each containing a PSI for the mother, and PSI for the father, PSI question booklet, a DBC-P questionnaire, and other self-report questionnaires not reported here) along with a pre-paid envelope were mailed to families who consented to the study. Mothers and fathers from the same family were instructed to answer the PSI items independently. Next, parents were interviewed by either a doctoral or master's level student using the VABS-II, to estimate their child's adaptive functioning. Interviews were conducted either over the phone, at participants' homes, or at the centre or school that their child attended. Interviews ranged from 30 minutes to an hour, depending on the child's level of functioning. The students administering the VABS-II received training on the measure and were shadowed on their administrations of it until they were deemed reliable, as assessed by the congruence of their ratings with those of the senior research assistant shadowing them.

Approximately two and a half years after parents participated in the initial testing, members of the NEIRI team contacted families to invite them to participate in a second round of data collection. For parents who agreed to continue with the study, appointments were scheduled with one of the NEIRI graduate students to complete the VABS-II interview. As at Time 1, interviews were conducted either over the phone, in person at participants' homes, or at the centre or school that the child attended. Following the VABS-II interview, parents were mailed packages containing forms identical to the ones

they completed at Time 1 (e.g., the PSI and the DBC-P, among others), along with pre-paid return envelopes.

## **Results**

### **Exploratory Data Analysis**

In order to assess whether the three EI sites were statistically similar, a profile analysis was conducted on the total Time 1 sample. Using the three variables of interest (child problem behaviour, adaptive functioning, and parent stress), no significant differences were found between the three sites. Thus, all subsequent analyses were run on the sample as a whole.

The number of cases was determined to be sufficient, given a ratio of 20 cases for every independent variable in the model (Tabachnick & Fidell, 2007). In the present study there were 56 participants at Time 1 and two independent variables (child problem behaviour and child adaptive functioning). The assumptions of skewness and kurtosis were both met, with neither value being above one. Linearity was assessed by examining the Q-Q plots. Linear relationships were found for all three of the variables. Histograms were plotted to test the assumption of normality. The data were found to be normally distributed. Neither multicollinearity nor singularity were found to be significant. Thus, the assumptions for multiple regression at Time 1 were met. Normality and linearity were checked for the Time 2 sample. Examination of the Q-Q plots, the normality histograms, and the skewness and kurtosis values revealed that both of these assumptions were met.

### **Hypothesis 1: Stress in Parents of Children with DD will be Predicted by Their Children's Behaviour Problems and Adaptive Functioning at Time 1**

In order to assess the relationship between parent stress and child behaviour problems and adaptive functioning, a Pearson correlation coefficient was computed using the Time 1 sample ( $n = 56$ ). A significant positive relationship was found between parent stress and child behaviour problems ( $r(54) = .73, p < .0001$ ) and a significant negative relationship was found between parent stress and child

adaptive functioning ( $r(54) = -.27, p < .05$ ). A multiple regression was performed using total parent stress as the outcome variable and child behaviour problems and child adaptive functioning as the predictor variables. The model was significant and explained 55% of the variance in parent stress ( $R^2 = .55, F(2, 53) = 32.15, p < .0001$ ). The only significant predictor of parent stress was child behaviour problems ( $\beta = .71, t(53) = 7.47, p < .0001$ ), with child adaptive functioning contributing only marginally to the model ( $\beta = -.112, t(53) = -1.28, p = .21, n.s.$ ).

### **Hypothesis 2: Child Behaviour Problems will Decrease from Time 1 to Time 2**

To test this hypothesis a paired samples  $t$  test was conducted using those participants for whom complete data was available from Time 1 and Time 2 ( $n = 21$ ), comparing child behaviour problems at Time 1 with child behaviour problems at Time 2. The difference was significant ( $t(19) = 2.13, p < .05$ ), and in the expected direction, with mean problem behaviour scores decreasing from Time 1 to Time 2 (Time 1  $M = 39.71$ , Time 2  $M = 32.52$ ).

### **Hypothesis 3: Child Adaptive Functioning will Improve from Time 1 to Time 2**

To evaluate this hypothesis, a paired samples  $t$  test was conducted using the Time 2 sample ( $n = 21$ ), comparing child adaptive functioning at Time 1 with child adaptive functioning at Time 2. The difference was not significant ( $t(19) = 1.95, p = .065, n.s.$ ).

### **Hypothesis 4: Parent Stress will Decrease from Time 1 to Time 2**

A paired sample  $t$  test was used to examine this hypothesis. Parent stress at Time 1 was compared to parent stress at Time 2. The difference was significant ( $t(19) = 3.58, p = .002$ ), and in the expected direction (Time 1  $M = 261.81$ , Time 2  $M = 243.48$ ).

### **Hypothesis 5: Child Behaviour Problems will Continue to be Related to Parent Stress at Time 2**

To test this hypothesis Pearson's correlation coefficients were computed using the Time 2 sample ( $n = 21$ ). Child behaviour problems were positively correlated with parent stress ( $r(19) = .74, p < .0001$ ).

**Hypothesis 6: Child Adaptive Functioning will Continue to be Related to Parent Stress at Time 2**

A Pearson correlation coefficient was computed using the Time 2 sample to ascertain the nature of the relationship between child adaptive functioning and parent stress. There was a significant negative correlation between child adaptive functioning and parent stress at Time 2 ( $r(19) = -.53, p < .05$ ).

**Summary**

The primary goal of this study was to examine the relationship between parent stress and child characteristics in families of children with DD who attend EI centres. Overall, the results provide support for the hypothesis that parent stress is related to child characteristics and that this relationship persists over time. Further, child characteristics predicted parent stress. However, contrary to the hypothesis, only problematic behaviours, and not adaptive functioning, were significantly predictive of parent stress. The next set of hypotheses proposing a decrease in child behaviour problems, an increase in adaptive functioning, and a decrease in parent stress from Time 1 to Time 2 were partially supported. Child behaviour problems and parent stress did decrease significantly over time but child adaptive functioning did not. The final set of hypotheses, concerning a continued correlation between parent stress and child characteristics over time were supported; at Time 2 both child problem behaviour and adaptive functioning were related to parent stress.

**Discussion**

In general, this research makes a significant contribution to the current discourse on the role of child characteristics on parent stress. The results underscore the importance of looking more closely at the relationship between child behaviour problems in children with DD and their parents' stress. The following discussion examines the implications of the results outlined above, beginning with the predictors of parent stress at Time 1, followed by the changes in problem behaviour, adaptive functioning, and parent stress from Time 1 to Time 2, and finally with the relationship between child

characteristics and parent stress at Time 2. The discussion ends by situating these results within the context of current research and practice and suggests areas for further research.

### **Predictors of Parent Stress at Time 1**

The finding that children's problematic behaviour was the most important factor when looking at parental stress in this sample is in line with a large body of research that has shown child behaviour to be one of the greatest predictors of stress in parents of children with DD (e.g., Baker et al., 2002; Baker et al., 2003; Bromley et al., 2004; Floyd & Gallagher, 1997; Friedrich et al., 1985; Hassall et al., 2005; Hastings & Brown, 2002; Hauser-Cram et al., 2001; Hodapp et al., 2003; Lach et al., 2009; Pisula, 2007; Quine & Pahl, 1991; Quine & Pahl, 1985). Across disabilities, problem behaviours are frequently reported as highly related to parent stress (e.g., Konstantareas and Homatidis, 1989; McDonald et al., 1996; Hassall et al., 2005; Raina et al., 2005; Tomanick et al., 2004; Fidler et al., 2000). Children with DD are more likely to experience behaviour problems than children without delays (e.g., Baker et al., 2003; Einfeld & Tonge, 1996). This is possibly due to specific characteristics of certain disabilities (Mitchell & Hauser-Cram, 2009). For instance, Eisenhower, Baker, and Blacher (2005) found that children with Cerebral Palsy and autism displayed the highest levels of behaviour problems, followed by children with undifferentiated delays, who were followed by children with Down syndrome and children without delays (these last two groups being indistinguishable with regards to behaviour problems). Guralnick (1999) reports that it may be children's cognitive functioning which is most significantly related to behavioural problems in children with DD, possibly because children with cognitive impairments often have difficulty with the self-regulation skills required for maintaining appropriate behaviour (Baker, Fenning, Crnic, Baker, & Blacher, 2007).

While child adaptive functioning was found to have a significant relationship with parent stress at Time 1, when the effect of child behaviour was accounted for, adaptive functioning did not predict parent stress. This result is contrary to both the guiding hypothesis and to numerous studies reporting

adaptive functioning to be a significant predictor of parent stress (Plant & Sanders, 2007b; Raina et al., 2000; Tomanik et al., 2004; Weiss et al., 2003). However, there are notable differences between these studies and the present one. First, all of the above studies had larger sample sizes than the current study, affording them better predictive power. Second, across the studies, various measures of both adaptive functioning and of parent stress were used, making comparison between studies difficult. Third, in some cases (e.g., Weiss et al., 2003) the age ranges of the individuals with DD were different from the age range used in the present study (birth to nine years of age). It is possible that with a larger and more diverse sample adaptive behaviour may actually be a significant predictor of parent stress.

However, many studies have also found that adaptive functioning does not predict parent stress. For instance, using identical measures to the ones employed in the present study, Hassall et al. (2005) found that adaptive behaviour was not significantly related with parenting stress. These authors found that of the child characteristics they examined, only problem behaviour was related with and predictive of parent stress. On the other hand, Mitchell and Hauser-Cram (2009) report that both children's adaptive functioning and their cognitive abilities were significant predictors of children's internalizing behaviours. Therefore, it is possible that there exists a relationship between children's adaptive functioning and their problem behaviour, a relationship which may lead to an indirect relationship between children's adaptive functioning and their parents' stress. This is a hypothesis which requires further investigation and would help to elucidate the relationship between child behaviour problems and parent stress.

### **Change in Problem Behaviours, Adaptive Functioning, and Parent Stress From Time 1 to Time 2**

Given that the goal of EI is to enhance the development of young children with DD and their families, it was hypothesized that participation in EI programs would facilitate a reduction in problem behaviours and an increase in adaptive functioning. Furthermore, given the relationship between parent stress and child characteristics, it was also hypothesized that if children's problem behaviours

decrease, and if their adaptive functioning improves, then parent stress would decrease over time. The first component of this hypothesis was confirmed: child behaviour problems decreased significantly from Time 1 to Time 2. Contrary to expectations, few studies report on a decrease in problem behaviour following EI. For the most part, studies of EI effectiveness examine improvements in children's social or adaptive behaviour, in their cognition, or in their language abilities, and this is primarily due to the emphasis in EI programs on pre-academic skills rather than on specific behaviours (e.g., Hauser-Cram et al., 2001; Mitchell & Hauser-Cram, 2009; Powell, Fixsen, Dunlap, Smith, & Fox, 2007). Studies that do report decreases in problem behaviour over time mostly evaluated specialized programs designed to identify and reduce problem behaviours. These can include functional communication training or functional behaviour assessment (e.g., Durand & Merges, 2008; Harding, Wacker, Berg, Winborn-Kemmerer, & Lee, 2009), behavioural parent training programs (e.g., Plant & Sanders, 2007a), or programs designed to reduce problem behaviours in older rather than younger children (e.g., Coughlin, Sharry, Fitzpatrick, Guerin, & Drumm, 2009). In the United States, remediation of behaviour problems is suggested in EI mandates, however this suggestion is made in such a way as to allow EI practitioners considerable freedom of interpretation when it comes to implementing programs aimed at reducing problem behaviour (Kaiser, 2007). Given the high correlation between child behaviour problems and parent stress, reduction of problematic behaviours would likely serve as a fruitful objective of EI in and of itself.

The hypothesis that children's adaptive functioning would improve over the course of the study was not supported. One possible explanation for this result may be found in the measure used to evaluate adaptive functioning. The VABS-II was normed as a measure of adaptive behaviour using samples of typically functioning children. Thus, the standard scores are based on the norms for a typical population of children. Children with DD often develop at a much slower rate than typically developing children. Therefore, changes in their adaptive functioning may not be accurately reflected

by the standard scores of this measure. An individual's raw scores could increase over time, while their standard scores actually decrease. In fact, Perry and colleagues (Perry et al., 2008) found that, using age equivalent scores on the VABS-II, children with autism improved on all domains of the measure from intake to discharge (between 4 to 48 months). However, when these researchers looked at the children's overall standard scores they found that motor scores remained stable, communication and language scores rose significantly, and daily living skills decreased significantly by exit. The authors also discovered that the pattern of results differed based on children's level of functioning. The highest functioning children saw significant improvement on the socialization and communication domains, but no change in their daily living skills; the children classified as having intermediate functioning experienced significant improvement in their communication skills, but no change in their socialization skills, and significant decreases in their daily living skills; finally, the lowest functioning children did not change significantly in their communication or socialization skills, and they too decreased significantly in their daily living skills. Perry et al. (2008) speculate that these decreases in daily living skills may be due to the lack of emphasis on promoting self-help skills in the intensive behavioural intervention programs the children attended. Another possible explanation advanced by the researchers is that children with autism may experience an unusual developmental trajectory in which daily living skills do not follow the same course as other areas of adaptive functioning, such as communication and socialization skills (Perry et al., 2008).

Other studies have found similar patterns of results, with several child characteristics being predictive of later adaptive skills functioning. For instance, Hauser-Cram et al. (2001) found that children's mental age was a partial mediator of adaptive behaviour in both the communication and daily living domains of the VABS. These researchers found that family patterns of interaction also significantly predicted later child adaptive behaviour. Hauser-Cram et al. (2001) used the Nursing Child Assessment Teaching Scale (NCATS) to measure mother-child interaction. The NCATS is an

observational rating scale that assesses teaching interaction between mothers and their children along four interaction domains: sensitivity to cues, response to distress, social-emotional growth fostering, and cognitive growth fostering. These researchers found that mothers with higher mother-child interaction scores and families with more positively rated family relations had children who experienced greater positive change in their socialization skills. Moreover, several child characteristics also predicted growth in daily living skills; children with higher mastery motivation at age three showed greater growth in the acquisition of daily living skills over time. In addition, children with fewer teacher-reported behaviour problems at age three experienced greater gains in mental age. Children's mental age, in turn, correlated positively with changes in the communication, socialization, and daily living skills domains of the VABS. The authors state that these two outcomes, combined with their findings concerning the relationship between children's adaptive functioning and mother-child interactions, family climate, and children's mastery motivation suggest that there exists a very complex relationship between all of these factors (Hauser-Cram et al., 2001). Thus, the developmental trajectories of children with DD cannot be considered in isolation and must include an investigation of the various intrinsic and environmental factors which affect them.

Parent stress is one such environmental variable. Stress in parents of children with DD has repeatedly been found to be higher than stress in parents of typically functioning children. For instance, using the Malaise Inventory as a measure of parent distress, Quine and Pahl (1985; 1991) found that 59% of mothers had malaise scores above the normal range, while Stores et al. (1998) report that 35% of mothers of children with Down syndrome and 46% of mothers of children with other intellectual disabilities had scores above the clinical cutoff, the point above which stress is considered to be clinically elevated and thus, may be associated with concomitant negative outcomes. Using the PSI, Tomanik et al. (2004) found that 66% of their sample exhibited clinically elevated depression, while Miodrag and Sladeczek (2009), found that 60% of mothers were clinically depressed. In the

present study, 48% of the longitudinal sample of parents reported clinically elevated levels of stress at Time 1. At Time 2, this figure had dropped, with 29% of the sample reporting clinically significant stress. Even for parents whose stress remained in the clinical range at Time 2, stress levels decreased significantly over the course of the study. In fact, all but three parents experienced a decrease in their stress from Time 1 to Time 2, and overall the decrease was significant for the sample as a whole. Thus, the hypothesis of a decrease in parent stress from Time 1 to Time 2 was supported, suggesting that this sample of parents was experiencing less stress at Time 2 follow-up than they were at the start of the study.

There are very few studies that have examined change in parent stress following participation in EI. In particular, few studies have investigated the possible relationship between parent stress and participation in EI programs aimed at improving child development. However, one such study that evaluated an eight-month home-based parent training program did just that. Küçüker (2006) reports that while mothers' stress scores did not decrease significantly, fathers' stress related to child characteristics did. Although maternal stress did not decrease over time, both mothers and fathers had significantly lower depression at follow-up. Several factors limit the generalization of these findings, including the small sample size ( $n = 29$  mothers and  $n = 28$  fathers of 29 children) and the particular format of the EI program (in-home parent training versus centre-based direct therapy for children). However, given the short period of time (eight months), it is nonetheless promising that the involvement of parents in behavioural training led to significant reductions in parent depression. Given the relationship that was found between child behaviour problems and parent stress in the present study, and given that both child behaviour problems and parent stress decreased, the results of the current study support the hypothesis of a persistent relationship between parent stress and child behaviour problems over time.

Hauser-Cram et al. (2001) have also reported on parental outcomes following participation in

EI. As mentioned previously, Hauser-Cram and her colleagues conducted a large-scale comprehensive longitudinal investigation of an EI program in the United States. Contrary to the findings of the present study, they report that parent stress increased between entry to EI (prior to the children's third birthdays) and follow-up when the children were 10 years old. For both mothers and fathers in Hauser-Cram et al.'s (2001) study, mother-reported child behaviour problems were a significant predictor of increased stress at age 10 follow-up; parents with children with more behaviour problems experienced significant increases in stress over time while parents of children with fewer behaviour problems had stress levels that remained stable and lower over time. For mothers only, stress levels correlated significantly with teacher-reported problem behaviour at age three as well. Contrary to the observed pattern of child-related stress, the parent-related stress of the parents in Hauser-Cram et al.'s (2001) study increased more gradually over time. However, there were differences based on the children's behaviour; mothers of children with high teacher-reported child behaviour problems at age three experienced steep increases in their parent-related stress over time, while mothers with low teacher-reported child behaviour problems at age three experienced significant decreases in parent-related stress over time. Dyson (1993) also found high stability in parent stress over time with parents of children with DD reporting significantly greater stress than parents of children without disabilities. In this sample of parents, stress related to parent and family problems and to pessimism increased over time for the parents of children with DD, while it remained constant for the parents of children without disabilities.

The present study looked only at overall parental stress, rather than breaking it down into child- and parent-related stress as other studies have done. Yet, the total stress score of the PSI is made up of both the child-related and parent-related stress domains of the measure. It is therefore a positive finding of the present study that this sample of parents became significantly less stressed over time.

**Relationship Between Child Characteristics and Parent Stress at Time 2**

As predicted, both child behaviour problems and adaptive functioning continued to be related to parent stress at Time 2. The parents of children with more behaviour problems experienced more stress at Time 2 than parents whose children had fewer behaviour problems. Likewise, parents of children with poor adaptive functioning reported more stress at Time 2 than parents whose children had better adaptive skills. Although the Time 2 sample was not large enough to run a regression analysis, it is speculated that since behaviour problems predicted parent stress at Time 1, and since both behaviour problems and parent stress decreased significantly from Time 1 to Time 2, behaviour likely continues to be an important predictor of parent stress at Time 2. This finding of a persistent relationship over time between parent stress and child behaviour is important because it supports theories of a bidirectional relationship between parents and their children (e.g., Guralnick, 2005). The family climate has been shown to significantly affect both child and parent development. Researchers currently investigating the role of harmonious family relationships in promoting positive development in families with children with DD advocate for more evidence-based family support that promotes improved behavioural outcomes for the children with DD (Mitchell & Hauser-Cram, 2009). Targeting child behaviour problems in the context of EI would thus appear to be a critical area of focus given the potential for reducing parent stress, and thus, reducing the negative effects that parent stress can have on child development (Ostberg, 1998; Secco et al., 2006). In fact, a meta-analysis conducted in 2007 by Dunst and colleagues (Dunst, Trivette, & Hamby, 2007) revealed that family-centred services improve parent well-being and also function to reduce child behaviour problems.

The relationship between child adaptive functioning and parent stress is less clear than the one found between child behaviour problems and parent stress. At both Time 1 and Time 2 parent stress and adaptive functioning were related, however, contrary to the hypotheses, adaptive functioning was not a significant predictor of parent stress at Time 1 and it did not improve from Time 1 to Time 2.

Thus, the relationship between adaptive functioning and parent stress may be an indirect one, or it may be that other factors not examined in the present study, such as social support (e.g., Miodrag & Sladeczek, 2009), coping resources (e.g., Lopes et al., 2008), and family-centred service provision (e.g., Dunst, 2000; Dunst et al., 2007; Guralnick, 2005) act to mediate or moderate the relationship between the two constructs.

### **Implications for Practice and Policy**

The results of the present study support a growing body of research that suggests that there is a bidirectional relationship between parent stress and child development in families of children with DD (e.g., Baker et al., 2003; Friedrick et al., 1985; Guralnick, 2005; Raina et al., 2005). Of particular importance, the present study used a Canadian sample of families in EI programs and studied them over time. Effective EI begins early and continues for a long period of time (e.g., Guralnick, 2008; Guralnick, Neville, Hammond, & Connor, 2008; Ramey & Ramey, 1992). There is a need to intervene early and quickly in order to minimize the negative effects on the family and promote positive, healthy development for both children with DD and their parents (Stores et al., 1998). Thus, studying parents' changing stress over the course of their participation in EI is qualitatively different from studying stress in parents of children with DD who do not necessarily attend EI programs. Currently, the main focus of EI programs is on promoting child development through various therapies aimed primarily at improving children's cognitive, language, and socialization abilities (Powell et al., 2007). Proponents of a family systems approach to EI have always insisted that the term "family" includes the child with DD, not just his or her parents (Dunst, 2000; Guralnick, 2005). Yet the child is often lost in discussions of family-centred EI, and this has led to researchers comparing and contrasting family-centred programs with child-focused, relationship-focused, or parent-child-focused interventions (Dunst, 2000). Being family-centred does not mean offering respite and support groups to parents or supporting their children through therapeutic interventions; in order to be a helpful model for the family as a whole, an

ideal conceptualization of EI must explicitly incorporate both parent and child features (Dunst, 2000; Guralnick, 2005). Child and parent needs are too often considered in isolation, ignoring the relationship that exists between them. The current study supports the idea that child characteristics and parent stress interact in a transactional way (Sameroff & Chandler, 1975), such that each serves to increase the other over time (Baker et al., 2003). This suggests that family-based interventions that focus on children's challenging behaviour are of primary importance if parent and child are to influence each other in positive ways (Bromley et al., 2004; Howlin, 1998).

The majority of parent stress research has been conducted in the United States. However, there are fundamental differences between Canada and the United States which may affect the generalizability of American results to Canada's population. For instance, in Canada it is the provincial and territorial governments that administer health and education services. There is no federal governing body to oversee these services. Thus, the services and funding to which families of children with DD have access can vary widely from province to province and territory to territory. While the current study is not large enough in either its scope or its sample size to make firm conclusions regarding changes to EI policy, it does shed light on the state of affairs in this country and it highlights the need for more longitudinal Canadian studies so that the situation of Canadian families of children with DD may be better understood, in order that supports and services may be tailored to the needs of Canada's population.

### **Limitations and Future Directions**

The present study has some limitations. The first is the small sample size. In order to have made firm conclusions regarding the amount of explained variance in parent stress due to either of the predictor variables at Time 2, a minimum sample size of 40 would have been required (Tabachnick & Fidell, 2007). Further, attrition rates were high, with fewer than half of Time 1 participants taking part at Time 2. The length of time in between testing points may have been a factor in attrition; for some

participants almost three years elapsed between Time 1 data collection and Time 2. Another possible factor in the attrition from this study may be the time required to complete the measures. Many parents indicated that they did not have time for a 30 to 60 minute VABS interview, and others stated that the package of questionnaires sent to their homes were too big (in addition to the two parent-report measures used in the present study, parents were also sent six other measures to complete at the same time). It is possible that the sample of parents who continued with the study at Time 2 is qualitatively different from the sample of parents who did not complete the measures at Time 2. The Time 2 participants may have had more free time to continue with the study, or may have been experiencing lower levels of stress or more social support, allowing them to better cope with the demands of the study. Future research should attempt to address sample size and attrition issues, perhaps by reducing the number of questionnaires employed and by asking parents what would make participation easier for them.

A second limitation is the make-up of the sample. The children had a wide range of DD and thus, a wide range of strengths and weaknesses. It has been argued that different disabilities cannot be lumped together and studied as one group because their phenotypic manifestations are too heterogeneous (Burack, 1990). For instance, Hodapp et al. (2003) and Fidler et al. (2000) report that children with Down syndrome show fewer behaviour problems than children with autism, and parents of children with Down syndrome report less stress than parents of children with autism. However, other studies have found that behaviour problems in children are the most significant predictor of parents' stress, regardless of disability (Floyd & Gallagher, 1994) or level of cognitive impairment (Baker et al., 2002). Therefore, the current sample was deemed acceptable. Nevertheless, comparisons between disabilities are an important area for future research; with larger sample sizes such comparisons may provide meaningful insight into the variation in parents' experience of stress.

A further sampling limitation is the lack of control for either age or sex of the children. Some

researchers have reported that child behaviours like hyperactivity and irritability differ with age (e.g., Stores et al., 1998) and that boys with DD may display more externalizing behaviours whereas girls with DD may display more internalizing behaviours, and these may differentially affect parent stress (e.g., Baker et al., 2002; Konstantareas & Homatidis, 1989; Stores et al., 1998).

With regard to the parents in this study, at both Time 1 and Time 2 over 90% of parents were married. This may reflect a selection bias with parents who are less stressed or who have more free time to participate taking part. Thus, the results may not generalize to single parents of children with DD. Future research should attempt to study a wider range of participants. Eliciting participation of single parents might require special incentives, such as child care. Consultation with single parents of children with DD might shed light on the factors limiting their participation in such studies.

A third limitation is the limited scope of the present study. There is a substantial body of research showing that environmental factors such as social support (e.g., Miodrag & Sladeczek, 2009) can affect parent well-being. The larger National Early Intervention Research Initiative from which the present sample was drawn includes data on a number of constructs which were beyond the scope of the present investigation (e.g., social support, perceptions of family-centred care, satisfaction with EI service provision, and the number and type of services accessed, to name a few). The present study examined only child behaviour problems and adaptive functioning in relation to parent stress. This particular focus was chosen due to the relative lack of research on the relationship between child characteristics and parent stress over time and it was believed to be an important area of study in and of itself. To better understand the association between parent stress and child characteristics, future research should incorporate an analysis of the environmental factors impacting families of children with DD.

A fourth limitation is the exclusive use of parent report measures. It is possible that the results reflect a rater bias given that the same parent whose stress scores were used also participated in the

VABS-II interview and rated the DBC-P. However, other studies that have controlled for rater bias by using teacher-reports of behaviour and adaptive functioning have found that the teacher and parent reports of child characteristics were similar and both were correlated with parent stress (e.g., Hauser-Cram et al., 2001; Quine & Pahl, 1985). Furthermore, while some studies have found higher teacher ratings of adaptive behaviour using the VABS, Voelker and colleagues (Voelker, Shore, Lee, & Szuszkiewicz, 2000) demonstrated that the survey edition of the VABS (used with parents) has norms for children under one year of age and contains more lower level items than the classroom edition (used with teachers) which has norms starting at three years of age. These researchers examined just the 169 overlapping items of the survey and classroom editions and found that when pairs of raters differed in their rating on identical items it was in fact parents rather than teachers who reported more advanced skills in 70% of comparisons. Thus, Voelker et al. (2000) conclude that discrepancies between parent and teacher ratings of adaptive functioning more likely reflect a classroom edition floor effect than a rater bias, and this is especially likely to be the case when studying lower functioning children for whom the classroom edition may not allow sufficient discrimination (Voelker et al., 2000). Nevertheless, future research might benefit by the inclusion of teacher-report measures, as well as direct child testing on the variables of interest.

A fifth limitation of the present study is the lack of a comparison group. Without a comparison sample of families of children with DD who are not attending EI programs it is impossible to say what effect the EI programs themselves may have had on the children's development or their parents' stress. A possible solution to this problem, which might be explored in future studies, is the addition of a wait-list control group that is not currently receiving EI services. This would allow a better understanding of any unique contribution of EI programming on child behaviour and parent stress. Given that it is unlikely for a family to be receiving absolutely no services while on a wait-list, clear delineation of the precise services and supports being accessed by the family, including the number of hours of service

and types of professionals administering the service, would further illuminate the complex factors affecting parent stress and is thus an important area for future research.

### **Contribution to Knowledge**

Aspects of the present study have been investigated by numerous researchers around the world. However, after a thorough search of the literature, no longitudinal Canadian studies were found that looked specifically at the relationship between parent stress and child behaviour problems and adaptive functioning in the context of EI. This is important for several reasons. First, the longitudinal nature of the present study helps to broaden current understanding of the way in which parent stress may change in parents of children with DD. Second, EI has been shown to be an effective means of bringing about change in children with DD. Thus, studying stress in parents of children with DD who attend EI programs may shed light on the complex relationship between the two constructs, eventually helping to inform current policy and practice.

### **References**

Abbeduto, L., Seltzer, M. M., Shatuk, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004).

Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile x syndrome. *American Journal on Mental Retardation*, 109, 237-254. Retrieved from <https://webvpn.mcgill.ca/http/vnweb.hwwilsonweb.com/hww/jumpstart.jhtml?recid=0bc05f7a67b1790ed7a0ad5f329b9ad0b0383c648fc858325290fbf9bb3cda1504b8f8f676794ee6&fmt=C>

Abidin, R. R. (1995). *Parenting Stress Index: Test Manual, Third Edition*. Odessa, FL: Psychological Assessment Resources.

American Association on Mental Retardation (2002). *Mental retardation: Definition, classification, and systems of supports: workbook - 10<sup>th</sup> edition*. Washington, DC: American Association on Mental Retardation.

- Baer, D. M. (1993). Quasi-random assignment can be as convincing as random assignment. *American Journal on Mental Retardation*, 97, 373-375.
- Bailey, D. B. Jr., & Powell, T. (2005). Assessing the information needs of families in early intervention. In M. J. Guralnick (Ed.), *The developmental systems approach to early intervention* (pp. 151-183). Baltimore, MD: Paul H Brookes Publishing Co.
- Bailey, D. B. Jr., & Wolery, M. (1992). *Teaching infants and preschoolers with disabilities, second edition*. Toronto, ON, Canada: Maxwell Macmillan Canada.
- Bailey, D. B. Jr., McWilliam, R. A., Darkes, L. A., Hebbeler, K., Simeonsson, R. J., Spiker, D., Wagner, M. (1998). Family outcomes in early intervention: A framework for program evaluation and efficacy research. *Exceptional Children*, 64, 313-328. Retrieved from <https://webvpn.mcgill.ca/http/proquest.umi.com/pqdlink?did=27744939&sid=1&Fmt=3&clientId=10843&RQT=309&VName=PQD>
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*, 107, 433-444. Retrieved from [http://vnweb.hwwilsonweb.com/hww/results/results\\_common.jhtml;hwwilsonid=52OJVRGLPBKVZQA3DINCFGOADUNGIIV0](http://vnweb.hwwilsonweb.com/hww/results/results_common.jhtml;hwwilsonid=52OJVRGLPBKVZQA3DINCFGOADUNGIIV0)
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230. doi: 10.1046/j.1365-2788.2003.00484.x
- Baker, J. K., Fenning, R. M., Crnic, K. A., Baker, B., & Blacher, J. (2007). Prediction of social skills in 6-year-old children with and without developmental delays: Contributions of early regulation and maternal scaffolding. *American Journal on Mental Retardation*, 112, 375-391. Retrieved from <http://vnweb.hwwilsonweb.com/hww/jumpstart.jhtml?recid=0bc05f7a67b1790ed7a0ad>

5f329b9ad0b0383c648fc85832ca62b6f518704e209c2f16853385c1e3&fmt=C

- Barnett, S. W. (1995). Long-term effects of early childhood programs on cognitive and school outcomes. *The Future of Children*, 5, 25-50. Retrieved from <http://www.jstor.org/stable/1602366>
- Baxter, C., Cummins, R. A., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual and Developmental Disability*, 25, 105-118. doi: 10.1080/13269780050033526
- Beckman, P. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation*, 95, 585-595.
- Bowlby, J. (1969/1982). *Attachment and loss. Volume I: Attachment*. New York: Basic Books.
- Boyd, R. D. (1998). Sex as a possible source of group inequivalence in Lovaas (1987). *Journal of Autism and Developmental Disorders*, 28, 211-215. doi: 10.1023/A:1026065321080
- Breslau, N., & Davis, G. C. (1986). Chronic stress and major depression. *Archives of General Psychiatry*, 43, 309-314. Retrieved from <https://webvpn.mcgill.ca/http/archpsyc.ama-assn.org/cgi/reprint/43/4/309>
- Brinker, R. P., Seifer, R., & Sameroff, A. J. (1994). Relations among maternal stress, cognitive development, and early intervention in middle- and low-SES infants with developmental disabilities. *American Journal on Mental Retardation*, 98, 463-480.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism: the International Journal of Research and Practice*, 8, 409-423. doi: 10.1177/1362361304047224
- Burack, J. A. (1990). Differentiating mental retardation: The two-group approach and beyond. In R. M. Hodapp, J. A. Burack, & E. Zigler (Eds.), *Issues in the developmental approach to mental retardation* (pp. 27-48). New York: Cambridge University Press.
- Burack, J. A., Hodapp, R. M., & Zigler, E. (1988). Issues in the classification of mental retardation:

Differentiating among organic etiologies. *Journal of Child Psychology and Psychiatry*, 29, 765-779. doi: 10.1111/j.1469-7610.1988.tb00752.x

Cantin, C., & Mottron, L. (2004). Pedagogy and specialized readaptation for primary school children with pervasive developmental disorder without mental retardation. *Revue de Psychoeducation*, 3, 93-115.

Cogill, S. R., Caplan, H. L., Alexandra, H., Robson, K. M., & Kumar, R. (1986). Impact of maternal postnatal depression on cognitive development of young children. *British Medical Journal*, 292, 1165-1167. doi: 10.1136/bmj.292.6529.1165

Congress of the U.S., Washington, D. C. House Committee on Education and Labor. (1986). *Education of the handicapped act amendments of 1986. Report* (Report No. House-R-99-860). Retrieved from [http://www.eric.ed.gov/ERICWebPortal/custom/portlets/recordDetails/detailmini.jsp?\\_nfpb=true&\\_ERICExtSearch\\_SearchValue\\_0=ED276165&ERICExtSearch\\_SearchType\\_0=no&accno=ED276165](http://www.eric.ed.gov/ERICWebPortal/custom/portlets/recordDetails/detailmini.jsp?_nfpb=true&_ERICExtSearch_SearchValue_0=ED276165&ERICExtSearch_SearchType_0=no&accno=ED276165)

Coughlin, M., Sharry, J., Fitzpatrick, C., Guerin, S., & Drumm, M. (2009). A controlled clinical evaluation of the parents plus children's programme: A video-based programme for parents of children aged 6 to 11 with behavioural and developmental problems. *Clinical Child Psychology and Psychiatry*, 14, 541-558. doi: 10.1177/1359104509339081

Dale, P. S., Jenkins, J. R., Mills, P. E., & Cole, K. N. (2005). Follow-up of children from academic and cognitive preschool curriculum at 12 and 16. *Exceptional Children*, 71, 301-317. Retrieved from <https://webvpn.mcgill.ca/http/proquest.umi.com/pqdlink?did=803872521&sid=2&Fmt=4&clientId=10843&RQT=309&VName=PQD>

Dawson, G., & Osterling, J. (1997). Early intervention and autism. In M. J. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 307-326). Baltimore, MD: Paul H Brookes Publishing Co.

Dekker, M. C., Koot, H. M., van der Ende, J., & Verhulst, F. C. (2002). Emotional and behavioral

problems in children and adolescents with and without intellectual disabilities. *Journal of Child Psychology and Psychiatry*, 43, 1087-1098. doi: 10.1111/1469-7610.00235

Den Heyer, I., & Kienapple, K. (2005). *Enhancing personnel preparation for early intervention in Nova Scotia*. Retrieved from the Centre of Excellence for Children & Adolescents with Special Needs website: <http://www.coespecialneeds.ca/PDF/enhancingpersonnelpreparation.pdf>

Diamond, K., & LeFurgy, W. (1992). Relations between mother's expectations and the performance of their infants who have developmental handicaps. *American Journal on Mental Retardation*, 97, 11-20. Retrieved from <https://webvpn.mcgill.ca/http/vnweb.hwwilsonweb.com/hww/jumpstart.jhtml?recid=0bc05f7a67b1790ed7a0ad5f329b9ad04574ef4eb0feab037f930b15e7785692b841cb0b1d30ecc1&fmt=C>

Dihoff, R. E., Brosvic, G. M., Kafer, L. B., McEwan, M., Carpenter, L., Rizzuto, G. E., . . . Bloszinsky, S. (1994). Efficacy of part- and full-time early intervention. *Perceptual and Motor Skills*, 79, 907-911.

Downey, G., & Coyne, J. C. (1990). Children of depressed parents: An integrative review. *Psychological Bulletin*, 108, 50-76. doi: 10.1037/0033-2909.108.1.50

Dunst, C. J. (2000). Revisiting "rethinking early intervention". *Topics in Early Childhood Special Education*, 20, 95-104. doi: 10.1177/027112140002000205

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered help-giving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 370-378. doi: 10.1002/mrdd.20176

Durand, V. M., & Merges, E. (2008). Functional communication training to treat challenging behavior. In J. E. Fisher (Ed.), *Cognitive behavior therapy: Applying empirically supported techniques in your practice (2nd ed.)* (pp. 222-229). Hoboken, NJ: John Wiley & Sons Inc.

Dyson, L. (1993). Response to the presence of a child with disabilities: Parental stress and family

functioning over time. *American Journal on Mental Retardation*, 98, 207-218.

Dyson, L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal on Mental Retardation*, 102, 267-279. Retrieved from <https://webvpn.mcgill.ca/http/vnweb.hwwilsonweb.com/hww/jumpstart.jhtml?recid=0bc05f7a67b1790ed7a0ad5f329b9ad04574ef4eb0feab0305eb3e92a41d7bc3de9ee84ff28a1e63&fmt=H>

Einfeld, S. L., & Tonge, B. J. (1992). *Manual for the developmental behavior checklist primary carer version*. School of Psychiatry, University of NSW, and Center for Developmental Psychiatry, Monash University.

Einfeld, S. L., & Tonge, B. J. (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: I rationale and methods. *Journal of Intellectual Disability Research*, 40, 91-98. doi: 10.1046/j.1365-2788.1996.767767.x

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research*, 49, 657-671. doi: 10.1111/j.1365-2788.2005.00699.x

Ello, L. M., & Donovan, S. J. (2005). Assessment of the relationship between parenting stress and a child's ability to functionally communicate. *Research on Social Work Practice*, 15, 531-544. doi: 10.1177/1049731505278928

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47, 385-399. doi: 10.1046/j.1365-2788.2003.00498.x

Erickson, M., & Upshur, C. C. (1989). Caretaking burden and social support: Comparison of mothers of infants with and without disabilities. *American Journal on Mental Retardation*, 94, 250-258.

- Essex, M. J., Klein, M. H., Cho, E., & Kraemer, H. C. (2003). Exposure to maternal depression and marital conflict: Gender differences in children's later mental health symptoms. *Journal of the American Academy of Child and Adolescent Psychiatry*, 42, 728-737. doi: 10.1097/01.CHI.0000046849.56865.ID
- Essex, M. J., Klein, M. H., Miech, R., & Smider, N. A. (2001). Timing of initial exposure to maternal major depression and children's mental health symptoms in kindergarten. *British Journal of Psychiatry*, 179, 151-156. Retrieved from <https://webvpn.mcgill.ca/http/bjp.rcpsych.org/cgi/content/abstract/179/2/151>
- Farran, D. C. (2000). Another decade of intervention for children who are low income or disabled: What do we know now? In J. P. Shonkoff, & S. J. Meisels (Eds.), *Handbook of early childhood intervention, second edition* (pp. 510-548). New York: Cambridge University Press.
- Farran, D. C., & Harber, L. A. (1989). Responses to a learning task at 6 months and I.Q. test performance during the preschool years. *International Journal of Behavioral Development*, 12, 101-114. doi: 10.1177/016502548901200106
- Feldman, M. A., Hancock, C. L., Rielly, N., Minnes, P., & Cairns, C. (2000). Behavior problems in young children with or at risk for developmental delay. *Journal of Child and Family Studies*, 9, 247-261. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=3560199&site=ehost-live>
- Feldman, M., McDonald, L., Serbin, L., Stack, D., Secco, M. L., & Yu, C.T. (2007). Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *Journal of Intellectual Disability Research*, 51, 606-619. doi: 10.1111/j.1365-2788.2006.00941.x
- Fewell, R. R., & Glick, M.P. (1996). Program evaluation findings of an intensive early intervention program. *American Journal on Mental Retardation*, 101, 233-243. Retrieved from <https://webvp>

n.mcgill.ca/http/vnweb.hwwilsonweb.com/hww/jumpstart.Jhtml?Recid=0bc05f7a67b1790  
ed7a0ad5f329b9ad04574ef4eb0feab03a9acfeaca948c9a62904cccd4efb72ea&fmt=H

Fidler, D. J., Hepburn, S. L., Mankin, G., & Rogers, S.J. (2005). Praxis skills in young children with Down syndrome, other developmental disorders, and typically developing children. *American Journal of Occupational Therapy*, 59, 129-138. Retrieved from [https://webvpn.mcgill.ca/http/find.galegroup.com/gtx/infomark.do?&contentSet=IAC-Documents&type=retrieve&tabID=T002&prodId=EAIM&docId=A208275767&source=gale&srcprod=EAIM&userGroupName=crepuq\\_mcgill&version=1.0](https://webvpn.mcgill.ca/http/find.galegroup.com/gtx/infomark.do?&contentSet=IAC-Documents&type=retrieve&tabID=T002&prodId=EAIM&docId=A208275767&source=gale&srcprod=EAIM&userGroupName=crepuq_mcgill&version=1.0)

Fidler, D. J., Hodapp, R. M., & Dykens, E. M. (2000). Stress in families of young children with Down syndrome, Williams syndrome, and Smith-Magenis syndrome. *Early Education and Development*, 11, 395-406. doi: 10.1207/s15566935eed1104\_2

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-aged children with disabilities and behavior problems. *Family Relations*, 46, 359-371. Retrieved from <http://www.jstor.org/stable/585096>

Foxx, R. M. (1993). Sapid effects awaiting independent replication. *American Journal on Mental Retardation*, 97, 375-376.

Friedrich, W. N., Wilturner, L. T., & Cohen, D. S. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Deficiency*, 90, 130-139.

Gallagher, J. J., Beckman, P., & Cross, A. H. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional Children*, 50, 10-19.

Glidden, L. M., & Jobe, B. M. (2006). Brief research report: The longitudinal course of depression in adoptive mothers of children with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 139-142. doi: 10.1111/j.1741-1130.2006.00067.x

Gomby, D. S., Larner, M. B., Stevenson, C. S., Lewit, E. M., & Behrman, R. E. (1995). Long-term

- outcomes of early childhood programs: Analysis and recommendations. *The Future of Children*, 5, 6-24. Retrieved from <http://www.jstor.org/stable/1602365>
- Grant, R. (2005). State strategies to contain costs in the early intervention program: Policy and evidence. *Topics in Early Childhood Special Education*, 25, 243-250. doi: 10.1177/0271121405025004050
- Guralnick, M. J. (1997a). Introduction: Directions for second-generation research. In M. J. Guralnick (Ed.), *The effectiveness of early intervention* (pp. xv-xvi). Baltimore, MD: Paul H Brookes Publishing Co.
- Guralnick, M. J. (1997b). Second-generation research in the field of early intervention. In M. J. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 3-20). Baltimore, MD: Paul H Brookes Publishing Co.
- Guralnick, M. J. (1999). Family and child influences on the peer-related social competence of young children with developmental delays. *Mental Retardation and Developmental Disabilities Research Reviews*, 5, 21-29. doi: 10.1002/(SICI)1098-2779(1999)5:1<21::AID-MRDD3>3.0.CO;2-O
- Guralnick, M. J. (2001). A developmental systems model for early intervention. *Infants and Young Children*, 14, 1-18. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2002051156&site=ehost-live>
- Guralnick, M. J. (2005). An overview of the developmental systems model for early intervention. In M. J. Guralnick (Ed.), *The developmental systems approach to early intervention* (pp. 3-28). Baltimore, MD: Paul H Brookes Publishing Co.
- Guralnick, M. J. (2008). International perspectives on early intervention: A search for common ground. *Journal of Early Intervention*, 30, 90-101. doi: 10.1177/1053815107313483
- Guralnick, M. J., Neville, B., Hammond, M. A., & Connor, R. T. (2008). Continuity and change from

full-inclusion early childhood programs through the early elementary period. *Journal of Early Intervention*, 30, 237-250. doi: 10.1177/1053815108317962

Harding, J. W., Wacker, D. P., Berg, W. K., Winborn-Kemmerer, L., & Lee, J. F. (2009). Evaluation of choice allocation between positive and negative reinforcement during functional communication training with young children. *Journal of Developmental and Physical Disabilities*, 21, 443-456. doi: 10.1007/s10882-009-9155-7

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognition in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49, 405-418. doi: 10.1111/j.1365-2788.2005.00673.x

Hastings, R. P., & Brown, T. (2002a). Behavior problems in children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation*, 107, 222-232. Retrieved from <https://webvpn.mcgill.ca/http/vnweb.hwwilsonweb.com/hww/jumpstart.jhtml?recid=0bc05f7a67b1790ed7a0ad5f329b9ad0b0383c648fc858324d64b08b6abba7e51466ce9a0bcd5573&fmt=C>

Hastings, R. P., & Taunt, H.M. (2002b). Positive perception in families of children with developmental disabilities. *American Journal on Mental Retardation*, 107, 116-127. Retrieved from <https://webvpn.mcgill.ca/http/vnweb.hwwilsonweb.com/hww/jumpstart.jhtml?recid=0bc05f7a67b1790ed7a0ad5f329b9ad0b0383c648fc85832dea32c64323bc4664265d1b51c91192b&fmt=C>

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., Krauss, M.W., Sayer, A., Upshur, C. C., & Hodapp, R. M. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development*, 66, i-viii+1-126. doi: 10.1111/1540-5834.00150

Haveman, M., van Berkum, G., Reijnders, 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. Retrieved from <http://www.jstor.org/stable/585101>
- Hodapp, R. M. & Burack, J. A. (2006). Developmental approaches to children with mental retardation: A second generation? In D. Cicchetti, & D. J. Cohen (Eds.), *Developmental psychopathology, vol 3: risk, disorder, and adaptation (2nd ed)* (pp. 235-267). Hoboken, NJ: John Wiley & Sons Inc.
- Hodapp, R. M., Ricci, L. A., Ly, T. M., & Fidler, D. J. (2003). The effects of the child with Down syndrome on maternal stress. *British Journal of Developmental Psychology*, 21, 137-151. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=9413950&site=ehost-live>
- Holmes, G. E., Britain, L. A., Simpson, R. L., & Hassanein, R. S. (1987). Developmental progress of five groups of disabled children attending an early intervention program. *Physical & Occupational Therapy in Pediatrics*, 7, 3-18. Retrieved from <https://webvpn.mcgill.ca/http/informahealthcare.com/toc/pop/7/1>
- Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal on Mental Deficiency*, 80, 431-436.
- Howlin, P. (1998). Practitioner review: Psychological and educational treatments for autism. *Journal of Child Psychology and Psychiatry*, 39, 307-322. doi: 10.1111/1469-7610.00327
- Jackson, A. P., Choi, J., & Bentler, P. M. (2009). Parenting efficacy and the early school adjustment of poor and near-poor black children. *Journal of Family Issues*, 30, 1339-1355. doi: 10.1177/0192513X09334603
- Jenkins, J. R., Dale, P. S., Mills, P. E., Cole, K. N., Pious, C., & Rork, J. (2006). How special education preschool graduates finish: Status at 19 years of age. *American Educational Research Journal*, 43, 737-781. doi: 10.3102/00028312043004737
- Jewell, J. D., Jordan, S. S., Hupp, S. D. A. & Everett, G. E. (2009). Etiology and relationships to developmental disabilities and psychopathology. In J. L. Matson (Ed.), *Social Behavior and Skills*

*in Children* (pp. 39-59). New York: Springer. doi: 10.1007/978-1-4419-0234-4\_3

Kaiser, A. P. (2007). Addressing challenging behavior: Systematic problems, systematic solutions.

*Journal of Early Intervention*, 29, 114-118. doi: 10.1177/105381510702900204

Kaiser, A. P., Yoder, P. J. & Keetz, A. (1992). Evaluating milieu teaching. In S. F. Warren, & J. Reichle (Eds.), *Causes and effects in communication and language intervention, volume 1* (pp. 9-47).

Baltimore, MD: Paul H Brookes Publishing Co.

Karagiannakis, A., Sladeczek, I., & Amar, D. (2009, September). *Early Intervention and Policy in*

*Canada*. Poster presentation at the Second European Network for Socio-Emotional Competence in Children (ENSEC) Conference, Izmir, Turkey.

Kazdin, A. E. (1993). Replication and extension of behavioral treatment of autistic disorder. *American Journal on Mental Retardation*, 97, 377-379.

Keller, K. M., & Fox, R. A. (2009). Toddlers with developmental delays and challenging behaviors.

*Early Child Development and Care*, 179, 87-92. doi: 10.1080/03004430600987126

Konstantareas, M. M., & Homatidis, S. (1989). Parental perception of learning-disabled children's adjustment problems and related stress. *Journal of Abnormal Child Psychology*, 17, 177-186.  
doi: 10.1007/BF00913792

Kouros, C. D., Merrilees, C. E., & Cummings, E.M. (2008). Marital conflict and children's emotional security in the context of parental depression. *Journal of marriage and family*, 70, 684-697.

doi: 10.1111/j.1741-3737.2008.00514.x

Kucuker, S. (2006). The family-focused early intervention programme: Evaluation of parental stress and depression. *Early Child Development and Care*, 176, 329-341. doi: 10.1080/03004430500206957

Lach, L. M., Kohen, D. E., Garner, R. E., Brehaut, J. C., Miller, A. R., Klassen, A. F., & Rosenbaum, P. L. (2009). The health and psychosocial functioning of caregivers of children with

neurodevelopmental disorders. *Disability and Rehabilitation*, 31, 607-618. doi: 10.1080/09638280802242163

Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.

Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing Company, Inc.

Linna, S. L., Moilanen, I., Ebeling, H., Piha, J., Kumpulainen, K., Tamminen, T., & Almqvist, F. (1999). Psychiatric symptoms in children with intellectual disability. *European Child & Adolescent Psychiatry*, 8, S77-S82. doi: 10.1007/PL00010704

Lopes, 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, 99-104. Retrieved from <http://www.oadd.org/publications/journal/issues/vol14no2/lopezEtAl.htm>

Lovaas, I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9. doi: 10.1037/0022-006X.55.1.3

Lyser, Y., Heinze, A., & Kapperman, G. (1996). Stress and adaptation in families of children with visual disabilities. *Families in Society: The Journal of Contemporary Human Services*, 77, 240-249. Retrieved from <http://proquest.umi.com.myaccess.library.utoronto.ca/pqdlink?did=9438860&sid=1&Fmt=4&clientId=12520&RQT=309&VName=PQD>

Maddux, J. E., Roberts, M. C., Sledden, E. A., & Wright, L. (1986). Developmental issues in child health psychology. *American Psychologist*, 41, 25-34. doi: 10.1037/0003-066X.41.1.25

Majnemer, A. (1998). Benefits of early intervention for children with developmental disabilities. *Seminars in Pediatric Neurology*, 5, 62-69. doi: 10.1016/S1071-9091(98)80020-X

Majnemer, A., & Limperopoulos, C. (2009). Outcomes in children with developmental disabilities. In M. Shevell (Ed.), *Neurodevelopmental disabilities: Clinical and scientific foundations* (pp. 470-

- 482). London: Mac Keith Press for the International Child Neurology Association.
- Majnemer, A., & Mazer, B. (2004). New directions in outcome evaluation of children with cerebral palsy. *Seminars in Pediatric Neurology*, 11, 11-17. doi: 10.1016/j.spen.2004.01.003
- Margalit, M., Shulman, S., & Stuchiner, N. (1989). Behavior disorders and mental retardation: The family system perspective. *Research in Developmental Disabilities*, 10, 315-326. doi: 10.1016/0891-4222(89)90019-X
- Martin-Doto, C. A. (2000). *The impact of respite, copying style, and child's adaptive functioning on parental stress* (Doctoral dissertation). York University, Toronto, ON, Canada.
- Martin, J. M., & Cole, D. A. (1993). Adaptability and cohesion of dyadic relationships in families with developmentally disabled children. *Journal of Family Psychology*, 7, 186-196. doi: 10.1037/0893-3200.7.2.186
- Mash, E. J., & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of Clinical Child Psychology*, 19, 313-328. doi: 10.1207/s15374424jccp1904\_3
- Mazer, B., & Majnemer, A. (2009). Service utilization and health promotion of children with neurodevelopmental disabilities. In M. Shevell (Ed.), *Neurodevelopmental disabilities: Clinical and scientific foundations* (pp. 426-482). London: Mac Keith Press for the International Child Neurology Association.
- McCall, R. B., Eichorn, D. H., Hogarty, P. S., Uzgir, I. C., & Schaefer, E. S. (1977). Transitions in early mental development. *Monographs of the Society for Research in Child Development*, 42, 1-108. Retrieved from <http://www.jstor.org/stable/1165992>
- McDonald, T. P., Couchonnal, G., & Early, T. (1996). The impact of major events on the lives of family caregivers of children with disabilities. *Families in Society: The Journal of Contemporary Human Services*, 77, 502-514. Retrieved from <http://proquest.umi.com.myaccess.library.uto>

ronto.ca/pqdlink?did=10264208&sid=7&Fmt=4&clientId=12520&RQT=309&VName=PQD

- Mesibov, G. B. (1993). Treatment outcome is encouraging. *American Journal on Mental Retardation*, 97, 379-380.
- Minnes, P. (1998). Mental retardation: The impact upon the family. In J. A. Burack, R. M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (pp. 693-712). Cambridge University Press.
- Miodrag, N., & Sladeczek, E. I. (2009). *Psychological well-being in parents of children with autism and Down syndrome* (Doctoral dissertation). McGill University, Montreal, QC, Canada.
- Mitchell, D. B., & Hauser-Cram, P. (2009). Early predictors of behavior problems: Two years after early intervention. *Journal of Early Intervention*, 32, 3-16. doi: 10.1177/1053815109349113
- Mundy, P. (1993). Normal versus high functioning status in children with autism. *American Journal on Mental Retardation*, 97, 381-384.
- Olsson, M. B., & Hwang, P.C. (2003). Influence of macrostructure of society on the life situation of families with a child with intellectual disability: Sweden as an example. *Journal of Intellectual Disability Research*, 47, 328-341. doi: 10.1046/j.1365-2788.2003.00494.x
- Osterberg, M. (1998). Parental stress, psychosocial problems and responsiveness in help-seeking parents with small (2-45 months old) children. *Acta Paediatrica*, 87, 69-76. doi: 10.1111/j.1651-2227.1998.tb01389.x
- Perry, A., Cummings, A., Geier, J. D., Freeman, N. L., Hughes, S., LaRose, L., . . . Williams, J. (2008). Effectiveness of intensive behavioral intervention in a large, community-based program. *Research in Autism Spectrum Disorders*, 2, 621-642. doi:10.1016/j.rasd.2008.01.002
- Piper, M. C., Gosselin, C., Gendron, M., & Mazer, B. (1986). Developmental profile of Down's syndrome infants receiving early intervention. *Child: Care, Health and Development*, 12, 183-194. doi: 10.1111/j.1365-2214.1986.tb00497.x

- Pisula, E. (2007). A comparative study of stress profiles in mothers of children with autism and those of children with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, 20, 274-278. doi: 10.1111/j.1468-3148.2006.00342.x
- Plant, K. M., & Sanders, M. R. (2007a). Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities*, 28, 362-385. doi:10.1016/j.ridd.2006.02.009
- Plant, K. M., & Sanders, M. R. (2007b). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disabilities Research*, 51, 109-124. doi: 10.1111/j.1365-2788.2006.00829.x
- Poehlmann, J., Clements, M., Abbeduto, L., & Farsad, V. (2005). Family experiences associated with a child's diagnosis of fragile X or Down syndrome: Evidence for disruption and resilience. *Mental Retardation*, 43, 255-267. doi: 10.1352/0047-6765(2005)43[255:FEAWAC]2.0.CO;2
- Powell, D., Fixsen, D., Dunlap, G., Smith, B., & Fox, L. (2007). A synthesis of knowledge relevant to pathways of service delivery for young children with or at risk of challenging behavior. *Journal of Early Intervention*, 29, 81-106. doi: 10.1177/105381510702900201
- Quine, L., & Pahl, J. (1985). Examining the causes of stress in families with severely mentally handicapped children. *British Journal of Social Work*, 15, 501-517. Retrieved from <https://webvpn.mcgill.ca/http/bjsw.oxfordjournals.org/content/vol15/issue5/index.dtl>
- Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transactional model of coping. *Journal of Community & Applied Social Psychology*, 1, 57-70. doi: 10.1002/casp.2450010109
- Quittner, A. L., Espelage, D. E., Opipari, L. C., Carter, B., Eid, N., & Eigen, H. (1998). Role strain in couples with and without a child with chronic illness: Associations with marital satisfaction, intimacy, and daily mood. *Health Psychology*, 17, 112-124. doi: 10.1037/0278-6133.17.2.112

- Quittner, A. L., Opipari, L. C., Regoli, M. J., Jacobsen, J., & Eigen, H. (1992). The impact of caregiving and role strain on family life: Comparisons between mothers of children with cystic fibrosis and matched controls. *Rehabilitation Psychology, 37*, 275-290. doi: 10.1037/h0079107
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., . . . Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115*, e626-e636. doi: 10.1542/peds.2004-1689
- Ramey, C. T., & Ramey, S. L. (1998). Early intervention and early experience. *American Psychologist, 53*, 109-120. doi: 10.1037/0003-066X.53.2.109
- Ramey, S. L., & Ramey, C. T. (1992). Early educational intervention with disadvantaged children - To what effect? *Applied & Preventative Psychology, 1*, 131-140. doi: 10.1016/S0962-1849(05)80134-9
- Richdale, A., Francis, A., Gavidia-Payne, S., & Cotton, S. (2000). Stress, behavior, and sleep problems in children with intellectual disability. *Journal of Intellectual and Developmental Disability, 25*, 147-161. doi: 10.1080/13269780050033562
- Ritzema, A. M., Saracino, J., & Sladeczek, I. E. (2010, March). Parents and early intervention: Satisfaction, coping, and family-centered care. Paper presentation at the annual meeting of the National Association of School Psychologists, Chicago, IL.
- Robins, F. R., Dunlap, G., & Plenis, A. J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention, 15*, 173-184. doi: 10.1177/105381519101500206
- Sameroff, A. J. & Chandler, M. J. (1975). Reproductive risk and the continuum of caretaking casualty. In F. D. Horowitz, M. Hetherington, S. Scarr-Salapatek, & G. Siegel (Eds.), *Review of child development research, Vol 4* (pp. 187-244). Chicago, IL: University of Chicago Press.
- Saridjan, N. S., Huizink, A. C., Koetsier, J. A., Jaddoe, V. W., Mackenbach, J. P., Hofman, A., . . .

Tiemeier, H. (2010). Do social disadvantage and early family adversity affect diurnal cortisol rhythm in infants? The generation R study. *Hormones and Behavior*, 57, 247-254.

doi: 10.1016/j.yhbeh.2009.12.001

Schopler, E., Short, A., & Mesibov, G. (1989). Relation of behavioral treatment to "normal functioning": Comment on Lovaas. *Journal of Consulting and Clinical Psychology*, 57, 162-164.

doi: 10.1037/0022-006X.57.1.162

Secco, M. L., Askin, D., Yu, C. T., Garinger, J., Mulaire-Cloutier, C., Scharf, L., . . . Feldman, M. A.

(2006). Factors affecting parenting stress among biologically vulnerable toddlers. *Issues in Comprehensive Pediatric Nursing*, 29, 131-156. doi: 10.1080/01460860600846867

Seifer, R., Clark, G. N., & Sameroff, A. J. (1991). Positive effects of interaction coaching on infants with developmental disabilities and their mothers. *American Journal on Mental Retardation*, 96, 1-11.

Seyle, H. (1956). *The stress of life*. New York: McGraw-Hill.

Shelton, K. H., & Harold, G. T. (2008). Interparental conflict, negative parenting, and children's adjustment: Bridging links between parents' depression and children's psychological distress.

*Journal of Family Psychology*, 22, 712-724. doi: 10.1037/a0013515

Siegel, B. (1996). Is the emperor wearing clothes? Social policy and the empirical support for full inclusion of children with disabilities in the preschool and elementary grades. *Social Policy Report: Society for Research in Child Development*, X, 2-17.

Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, 111, 155-169.

Retrieved from [https://webvpn.mcgill.ca/http/vnweb.hwwilsonweb.com/hww/jumpstart.jhtml?](https://webvpn.mcgill.ca/http/vnweb.hwwilsonweb.com/hww/jumpstart.jhtml?recid=0bc05f7a67b1790ed7a0ad5f329b9ad0b0383c648fc85832b07c20287c0b0e34d7bdc0176974565e&fmt=C)

recid=0bc05f7a67b1790ed7a0ad5f329b9ad0b0383c648fc85832b07c20287c0b0e34d7bdc0176974565e&fmt=C

- Sladeczek, E. I., & Amar, D. (2005). *A dynamic assessment of early intervention models in children with developmental delays: Creating a paradigm shift in early intervention policy and practice*. Unpublished grant proposal.
- Sladeczek, E. I., & Amar, D. (2009). *Summary of the Max Bell Foundation funded project: A dynamic assessment of early intervention models in children with developmental delays*. Unpublished summary report.
- Smith, T., Klevstrand, M., & Lovaas, O. I. (1995). Behavioral treatment of Rett's disorder: Ineffectiveness in three cases. *American Journal on Mental Retardation*, 100, 317-322.
- Solomon, M., Ono, M., Timmer, S., & Goodlin-Jones, B. (2008). The effectiveness of parent-child interaction therapy for families of children on the autism spectrum. *Journal of Autism and Developmental Disorders*, 38, 1767-1776. doi: 10.1007/s10803-008-0567-5
- Sparrow, S. S., Cicchetti, D. V. & Balla, D. A. (2005). *Vineland adaptive behavior scales: Test manual, second edition*. Bloomington, MN: Pearson Assessments.
- Spence, S. H., Najman, J. M., Bor, W., O'Callaghan, M. J., & Williams, G. M. (2002). Maternal anxiety and depression, poverty and marital relationship factors during early childhood as predictors of anxiety and depressive symptoms in adolescence. *Journal of Child Psychology and Psychiatry*, 43, 457-469. doi: 10.1111/1469-7610.00037
- Spiker, D., & Hopmann, M. R. (1997). The effectiveness of early intervention for children with Down syndrome. In M. J. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 271-305). Baltimore, MD: Paul H Brookes Publishing Co.
- Stein, M. A., Szumowski, E., Blondis, T. A., & Roizen, N. J. (1995). Adaptive skills dysfunction in ADD and ADHD children. *Journal of Child Psychology and Psychiatry*, 36, 663-670. doi: 10.1111/j.1469-7610.1995.tb02320.x
- Stores, R., Stores, G., Fellows, B., & Buckley, S. (1998). Daytime behaviour problems and maternal

stress in children with Down syndrome, their siblings, and non-intellectually disabled and other intellectually disabled peers. *Journal of Intellectual Disability Research*, 42, 228-237. doi: 10.1046/j.1365-2788.1998.00123.x

Stuhec, V., Gisel, E. G. (2003). Compliance with administration procedures of tests for children with pervasive developmental disorders: Does it exist? *Canadian Journal of Occupational Therapy*, 70, 33-41. Retrieved from <https://webvpn.mcgill.ca/http/proquest.umi.com/pqdlink?did=295004111&sid=1&Fmt=4&clientId=10843&RQT=309&VName=PQD>

Szatmari, P., Archer, L., Fisman, S., Streiner, D. L., & Wilson, F. (1995). Asperger's syndrome and autism: Differences in behavior, cognition, and adaptive functioning. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34, 1662-1671. Retrieved from [https://webvpn.mcgill.ca/http/ovidsp.tx.ovid.com/sp-2.3.1b/ovidweb.cgi?&S=GFNGFPFMBODDIBKCMCEL LGNKOGIOAA00&Link+Set=S.sh.15.17.20.41|17|sl\\_10](https://webvpn.mcgill.ca/http/ovidsp.tx.ovid.com/sp-2.3.1b/ovidweb.cgi?&S=GFNGFPFMBODDIBKCMCEL LGNKOGIOAA00&Link+Set=S.sh.15.17.20.41|17|sl_10)

Tabachnick, B. G., & Fidell, L.S. (2007). *Using multivariate statistics, fifth edition*. Montreal, QC, Canada: Pearson Allyn & Bacon.

Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviour exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, 29, 16-26. doi: 10.1080/13668250410001662892

Trute, B., Worthington, C., & Hiebert-Murphy, D. (2008). Grandmother support for parents of children with disabilities: Gender differences in parenting stress. *Families, Systems, & Health*, 26, 135-146. doi: 10.1037/1091-7527.26.2.135

U.S. Department of Education (2002). *To assure the free, appropriate public education of all children with disabilities: Twenty-fourth annual report to Congress on the implementation of the Individuals with Disabilities Education Act, Section IV, Results*. Retrieved from <http://www.ed>

gov/about/reports/annual/osep/2002/section-iv.pdf

- Venetsanou, F., & Kambas, A. (2010). Environmental factors affecting preschoolers' motor development. *Journal of Early Childhood Education*, 37, 319-327. doi: 10.1007/s10643-009-0350-z
- Vig, S., & Jedrysek, E. (1995). Adaptive behavior of young urban children with developmental disabilities. *Mental Retardation*, 33, 90-98.
- Voelker, S. L., Shore, D. L., Lee, C. H., & Szuskiewicz, T.A. (2000). Congruence in parent and teacher ratings of adaptive behavior of low-functioning children. *Journal of Developmental and Physical Disabilities*, 12, 367-376. doi: 10.1023/A:1009436230984
- Weiss, J. A., Sullivan, A., & Diamond, T. (2003). Parent stress and adaptive functioning of individuals with developmental disabilities. *Journal on Developmental Disabilities*, 10, 129-135. Retrieved from <http://www.oadd.org/publications/journal/issues/vol10no1/tableOfContents.htm>
- Zigler, E., & Hodapp, R. (1986). *Understanding mental retardation*. New York: Cambridge University Press.