Differences in Stress and Needs Identified by Mothers of Young Children with Developmental Disabilities at Point of Entry into the Service System

By

Allison Newton

A Thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfillment of the requirements of the degree of

MASTER OF SOCIAL WORK

Faculty of Social Work
University of Manitoba
Winnipeg

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES

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Abstract

The impact of having a child with developmental disabilities has drawn increasing attention in recent years. Many factors have been explored as affecting parental and family outcome such as child characteristics, formal and informal supports, and internal family resources. The purpose of this study was to examine (a) whether the child's age at point of entry into the service system is related to maternal parenting stress, and (b) whether there is an association between needs for support identified by mothers of children at different age levels at point of entry into the service system and maternal parenting stress. The key findings were (a) maternal parenting stress increased with the age of the child, (b) mothers of infants with disabilities reported less child-related stress than mothers of pre-school and school-age children with disabilities, (c) parenting stress was associated with the need for information, family and social support, and help explaining the disability.

Acknowledgements

I would like to acknowledge the roles of several people, without whom the completion of this thesis would not have been possible.

To begin I must thank Dr. Diane Hiebert-Murphy, my advisor, whose encouragement, support, guidance, wisdom, intelligence, patience and warmth kept me going and got me through this process. Without her input and editing this work would not be what it is. I also thank my committee members, Dr. Barry Trute and Dr. Jason Brown for their support and their flexibility throughout the thesis process.

I thank Dr Diane Hiebert-Murphy and Dr Brarry Trute for allowing me to participate in the Family Strengths Research Project and allowing me to use a portion of the data for the research of this thesis.

I thank my parents Jim and Marguerite Newton for their support in all of its forms, too many and varied to name.

Finally, I thank Jared Steinfeld for all of the technical assistance along the way, for embracing and supporting me, for his faith in me and for his love.

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Differences in Stress and Needs Identified by Mothers of Young Children with Developmental Disabilities at Point of Entry into the Service System

The impact of parenting a child with developmental disabilities has drawn attention in the past several decades as awareness and understanding of disabilities has increased in response to the movement towards a model of community inclusion. Where a movement towards institutionalization marked the 19th century, the 20th century moved away from the segregation of individuals with disabilities (Seligman & Darling, 1989). With this shift, the family unit has become responsible for the primary care giving role of children with disabilities. Much research has focused on identifying and examining variables (i.e., child characteristics, formal and informal supports, and internal family resources) affecting outcomes for families of children with developmental disabilities as researchers attempt to understand how to best direct services to produce the most positive outcomes for families. Recent research, such as that by Hendrickson, Baldwin, and Allred (2000), Redmond and Richardson (2003), Mitchell and Sloper (2002), Brett (2004), and Abelson (1999) has begun to examine the impact that the service system has on family outcomes and how to best direct resources to address the challenges and needs that families experience raising a child with disabilities.

Developmental disability is defined as a severe, chronic impairment creating functional limitations in three or more of the following areas: self-care, language, learning, mobility, and self-direction. The condition can be attributed to one or more mental or physical impairments that begin before the individual reaches 22 years of age (Binstock, 1997). For the purposes of this paper, developmental disability will be defined broadly and encompass a range of disabilities that involve developmental delay or impairment in functioning.

In addition to the normative challenges of parenting infants and small children, there are many challenges specific to raising a child with developmental disabilities that may affect the level of stress a family experiences. Baxter, Cummins, and Polak (1995) conducted a longitudinal study examining parental stress levels as reported by parents regarding their child with a disability as well as their youngest child without a disability throughout several life stages. In all instances parents reported higher levels of stress associated with the child with a disability, with the highest stress period being during the process of diagnosis.

Boss (2002) defines family stress as "pressure on the family. It is a disturbance of the family's steady state- that is, the system is upset, pressured, disturbed, and not at rest. Therefore, family stress is change in the family's equilibrium" (p. 61). Boss goes on to explain that stress within the family is not necessarily bad, but becomes problematic when the stress reaches a level that is too high or too low. Family adjustment as defined by McCubbin and Patterson (1983) is the short-term process "which families use to achieve stability in the face of stressful normative and non-normative life events and transitions" (p.19). When families adjust to maintain family equilibrium the rules, roles, and relationships are modified but not redefined.

Early research, such as that by Fortier and Wanlass (1984) assumed that the diagnosis of a disability would lead to a state of crisis for the family. Boss (2002) defines family crisis as:

> (a) a disturbance in the equilibrium that is so overwhelming, (b) a pressure that is so severe, or (c) a change that is so acute that the family system is blocked, immobilized, and incapacitated. At least for a time, the family does not function. Family boundaries are no longer maintained, customary roles and tasks are no longer performed, and family members can no longer function at optimal levels, physically or psychologically. (pp. 62-63).

More recent research suggests that while for some families the diagnosis of a developmental disability and the challenges of raising a child with a developmental disability may be a source of stress or crisis, many families are able to manage the stress and the challenges and even experience positive changes as a result of parenting a child with a disability (Scorgie & Sobsey, 2000; Trute, 1990, 1995; Trute & Hauch, 1988; Trute & Hiebert- Murphy, 2002). An important area of research is to determine what variables account for the differences between families who manage the stressors associated with raising a child with developmental disabilities and those who experience a state of crisis.

In order to support families of children with disabilities we need to understand and recognize the variables that affect outcome. By understanding these factors, services can be designed to be proactive in addressing the needs of families, and tailored to address specific needs in the most appropriate and effective way.

Variables Affecting Family Stress

Child Characteristics

Research examining the effects of child characteristics on family stress and outcome has examined variables such as diagnosis, responsiveness, behavior, level of delay or disability, gender, and age.

Diagnosis/ responsiveness/ behavior/ level of disability. Due to the interrelated nature of the variables of diagnosis, responsiveness, behavior, and level of disability, these variables are difficult to discuss in isolation from each other. Investigations into the impact of diagnosis on parental coping have yielded interesting results. Families of children with an autism spectrum disorder have been found to experience significantly higher levels of depression and stress compared with families of children with other disabilities or children without disabilities (Bouma & Schweitzer, 1990; Holroyd & McArthur, 1980; Noh, Dumas, Wolf, & Fisman, 1989; Rodrigue, Morgan & Geffken, 1990). Siegel (1996) suggests that the characteristic of lack of responsiveness to affection, common to children with autism, contributes to an increase in parenting stress. Responsiveness is one of the five child characteristics explored by Beckman (1983) as related to parental stress. Beckman examined rate of child progress, responsiveness, temperament, repetitive behavior patterns, and additional or unusual care giving demands in relation to parenting stress among parents of 31 infants with disabilities and found that all of these characteristics, with the exception of rate of progress, were significantly related to amount of stress reported. Boyce and Behl (1991) demonstrate findings similar to those of Beckman, suggesting that responsiveness and behavior patterns, not the developmental functioning level of the child are related to stress. Dumas, Wolf, Fisman, and Culligan (1991) found that parents of children with behavior disorders experience significantly higher levels of dysphoria and parenting stress than parents of children with Down syndrome or children without disabilities. Bouma and Schweitzer (1990) provide empirical support that chronic mental disorders in children contribute more to family stress than chronic physical illness. They support Beckman's findings that stress reported by mothers correlated with child temperament, responsiveness, behavioral patterns, and care giving demands.

Studies comparing mothers with children with a range of developmental disabilities to mothers of children without disabilities demonstrate that the experience of parenting a child with any developmental disability is more challenging than parenting a child without disabilities (Dyson, 1997; Gowen, Johnson-Martin, Goldman, & Appelbaum, 1994; Wilton & Renaut, 1986). In a comprehensive, quantitative comparison of stress between the two groups, Wilton and Renaut (1986) administered the

Questionnaire on Resources and Stress (QRS) to 42 mothers of pre-schoolers with a developmental disability and a group of 42 mothers of pre-schoolers without disabilities. The pre-schoolers without disabilities were matched to the sample of children with developmental disabilities on age, gender, and socio-economic status. The results showed that mothers of infants with developmental disabilities reported significantly higher levels of stress on 13 of 15 QRS scales.

Research by Dumas et al. (1991) is an exception to the above findings of increased challenges of parenting a child with any developmental disability over children without disabilities. Dumas et al. found that while parents of children with autism and behavioral problems experience higher levels of stress than parents of children without disabilities, parents of children with Down syndrome were found to have levels of parenting stress comparable with parents of children without disabilities. Dumas et al. utilized well-established measures including The Parenting Stress Index (Abidin,1995), The Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), and The Eyberg Child Behavior Inventory (Eyberg, 1999) to measure parenting stress, parental dysphoria, and child behavior problems respectively. They also had a sample size of 150 with a well-matched control group. As noted above, affection and responsiveness are significant variables influencing parenting stress (Siegel, 1996). Perhaps the variables of high affection and responsiveness, characteristic of children with Down syndrome

(Holroyd & McArthur, 1976), serve to mediate the stressor of parenting a child with a developmental disability.

Of the child related variables of diagnosis, responsiveness, behavior, and level of disability, responsiveness and behavior seem to most significantly affect parenting stress. Data suggests that diagnosis also affects parenting stress, however, the differences in behavior and responsiveness associated with specific diagnoses may be the reason for increased parental stress reported among parents of children with certain diagnoses. Finally, existing research suggests that level of disability or impairment does not affect parenting stress of parents of children with developmental disabilities. Because the above child related characteristics are inter-related additional research needs to be conducted to better understand the relationship between child-related characteristics and parenting stress.

Gender. Studies of the relationship between child gender and parenting stress have produced mixed results. Boyce and Behl (1991) found that parents of female children with disabilities have higher levels of parental adjustment than do parents of male children with disabilities. Similarly, higher levels of parental anger have been reported by parents of male children compared to parents of female children with autism (Gray & Holden, 1992). Other studies have found no differences in adjustment between parents of male or female children with developmental disabilities (Beckman, 1983; Sloper, Knussen, Turner, & Cunningham, 1991). Trute (1995) found higher rates of depression among fathers of male children with disabilities compared to fathers of female children with disabilities, particularly when the disability is less severe. Seligman and Darling (1989) suggest that fathers are more concerned about the perception of future social success of their male children than their female children and compared to mothers. Across most cultures males are expected to be stronger and more independent than females thus a male with disabilities poses a greater challenge to social norms. Further research may be useful in developing a better understanding of the significance of the variable of child gender in parenting outcomes.

Child age. Research regarding parenting outcome and the characteristic of child age has also produced contradictory results. Beckman (1991), Dumas et al. (1991), and Baxter et al. (1995), all found parenting stress to be most intense in mothers of young children with disabilities. Flint and Wood (1989), Cameron and Orr (1989), and Boyce and Behl (1991) found that child's age was unrelated to parenting stress. Gray and Holden (1992) looked at age of children with autism as a variable affecting parental reports of anger. They found higher levels of anger reported among parents of younger children. A noteworthy finding of Gray and Holden's work is the negative correlation between child age at onset of autism and rates of parental anxiety and depression. Gray and Holden suggest that this correlation may be indirectly related to the degree of impairment however further research would need to be conducted to draw conclusions about these findings. While child age has been explored as a variable affecting parental outcome, I have been unable to locate any research on child age at time of entry into the formal service system as a variable affecting parenting stress. Most of the data obtained on child age and parenting stress have treated child age as a continual variable rather than as distinct groups. Flint and Wood (1989) look at three distinct age groups, however they do not provide a rationale for selecting the specific age groupings. The categories Flint and Wood selected were 6 to 9 years, 12 to 15 years, and 18 to 21 years. Flint and Wood found no relation between child age and parenting stress, however, different age groupings may yield different results. Byrne and Cunningham (1985) suggest that it may be more beneficial to consider stages in the family life cycle rather than child age as a factor influencing family stress. Wikler (1981) points to times of transitions as a more salient factor influencing family stress than child chronological age as a continuous variable.

Experience of Diagnosis

In a study of parents of children with autism, Gray (2002) describes the period prior to the diagnosis, when the child's problems become more pronounced, as highly stressful. During this time parents begin to realize that their child is not developing typically and may be exhibiting challenging behavior, however they do not have any explanation for this or any formal support. The ambiguity families feel when they believe that something is wrong with their child but do not have a diagnosis increases the stress experienced. Avdi, Griffin, and Brough (2000) describe the conflicted feelings parents experience when they receive a delayed diagnosis as "both a relief and terribly distressing, while not receiving a diagnosis was represented as creating an almost untenable position of uncertainty" (p. 251). This is consistent with Boss' (2002) discussion of ambiguity as one of the components of chronic stressors. An area for further research may be to explore the relationship between family functioning and how quickly a diagnosis and planning follow suspicions that the child may not be developing typically.

The most useful support professionals can offer families during the time of diagnosis is clear and timely information regarding both the diagnosis and the prognosis (Nissenbaum, Tollefson, & Reese, 2002). Parents also need ongoing support following the diagnosis as they gradually absorb the information and questions arise about the future and how to best meet the special needs of the child and their family.

Formal Support

Service barriers. To manage the ongoing pressures on family life associated with raising a child with a developmental disability, many families rely on the support of formal services in their community. In a qualitative study of 17 mothers of children (birth to 4 years) with severe/ profound disabilities Redmond and Richardson (2003) found that most mothers reported barriers to obtaining the services required. The common complaints were a lack of consistency with services and information, long waiting periods to obtain required services, lack of coordination between service providers, inadequate financial support for the costs associated with raising a child with high care/

medical needs, and barriers to access due to rigid eligibility criteria regarding age and location. The mothers also reported that services that were offered were often not useful, as they did not address the unique needs of individual families. Hendrickson, Baldwin, and Allred (2000) conducted a similar qualitative study of maternal reports of barriers to service. Hendrickson et al. interviewed 13 mothers of infants (birth to 2 years). The common themes in this study were a lack of information regarding both the diagnosis and services for which the family was eligible. These themes were replicated in the Redmond and Richardson study. Likely the absence of reports of the other barriers reported by Redmond and Richardson was due to the younger age of the children in the sample. Many of the parents in the Hendrickson et al. study had experienced barriers to access of services but had not yet had experience with the services that were reported by Redmond and Richardson. Another theme that arose in the Hendrickson et al. study was mothers' concern that physicians acted as the "gatekeepers" to services. The mothers reported frustration with the lack of information they were provided by their children's physician because of the physician's lack of knowledge of disabilities and available services.

A barrier to services identified and explored by Brett (2004) in a phenomenological study of six parents of children with disabilities is the difficulty some parents experience with accepting support. The initial recognition parents have that they may require support to continue to parent their child with a disability can be an emotionally difficult experience. Parents report feeling as though they have failed as parents if they are unable to meet all of the needs of their child and their family. If parents have had difficulty accepting that their child has a disability, the process of accepting support may require that they confront this and experience painful emotions associated with the diagnosis. The implication this research has on practice is that a need many parents may have when initially accepting support is for professionals to be sensitive to the feelings they may have about accepting support. Parents may decline offers of support several times before they feel ready to accept it. The parents in the Brett (2004) study also expressed a need to feel included in the planning and implementation of support. Professionals need to recognize parents as the experts on their child and interact with them accordingly. Judge (1998) concludes that the most effective model of delivery of formal services to families is a model that “mirrors” informal supports and responds to needs identified by the family.

Related to barriers to service is the issue of how families access formal services and what their experiences are throughout the process. Very little research to date has looked at the experience of parents seeking services for their children with special needs. Arcia, Fernandez, Jaquez, Castillo, and Ruiz (2004) conducted research on this issue by conducting interviews with 62 Latina mothers of children with disruptive behaviors who were first time help seekers. While this research may not be generalizable to a broader population, it does shed some insights into different modes of entry into formal services. Arcia et al. identified four modes of entry into formal services with the norm being "entry through a laborious and convoluted path following multiple indications of problem behaviors" (p. 1217). Other modes of entry identified by Arcia et al. from their interviews were entry through coercion, entry through acceptance of referral, and entry through responsive and resourceful action. Given the research findings on barriers to services reported by parents of children with disabilities as described above, the findings of Arcia et al. are not surprising. The findings suggest that professionals need to reevaluate existing service structures and address issues of access. Research into the experience of families gaining access to formal services with a broader population of families of children with a variety of developmental disabilities would provide further support for improving access to services if findings prove to be similar to those of Arcia et al.

Service needs. Redmond and Richardson (2003) explored mothers' wishes for how services could best meet their needs. The mothers most frequently described ideal services as consistent, reliable, and home based. Mitchell and Sloper (2002) investigated parents' wishes for service delivery, specifically the mode of delivery of information. Mitchell and Sloper found that parents reported a desire to have a key person identified to facilitate the provision of information, communication between the families and the various service providers, and assistance with understanding and appropriately managing the often-overwhelming amount of information. The other significant response of parents was the desire to have information communicated verbally and in written form.

To help families and service providers accurately identify and understand the needs of individual families, Bailey and Simeonsson (1988) developed an assessment tool, The Family Needs Survey. This measure assesses the needs of families with children with disabilities in the areas of need for information, support, explaining to others, community services, financial support, and assistance with family functioning. In their study of 34 two-parent families, Bailey and Simeonson found that more than 50% of the mothers identified the following eight unmet needs: information on how to teach their child, information regarding the child's condition or disability, information about available services at present and in the future, support in having more time for themselves, financial support for expenses such as food, housing, clothing, or transportation, assistance obtaining reading materials about other families with children with similar conditions, and opportunities to meet and speak with other parents with children with similar conditions. Less than 10% of mothers in the study reported a need for assistance in obtaining employment, getting appropriate childcare during religious services, more time to speak with the child's teacher or therapist, and assistance locating a doctor who understands their needs and those of their child. Further research needs to be conducted in order to obtain information on the needs of single parents and parents of older children with disabilities.

Informal Support

Informal supports are regarded as an important external resource for families of children with disabilities in mediating parental stress. Emotionally supportive extended family, practical supports such as childcare offered by family or friends, connections with other parents of children with disabilities, or involvement in a religious or community group have all been found to strengthen a family's ability to function (Abbott & Meredith, 1986). Judge (1998) studied 69 parents, primarily mothers, of children with disabilities from birth to 5 years of age, and found significant levels of positive adjustment among parents who seek out social support. Trute and Hauch (1988) studied a sample of 40 families identified as having positively adjusted to the birth of child with a developmental disability. Trute and Hauch found that their sample of families "displayed a high level of employment of social network resources in an appropriate, efficient manner." (p.191). In particular Trute and Hauch found a strong support system among the extended family members of their sample of families. The extended family supports were characterized as "small, intense" systems "providing tangible help, physical assistance, and emotional aid" (p. 191).

As studies began to demonstrate the salience of informal support networks as mediators of parenting stress, the focus of the research began to determine the variables required for a support network to be of greatest impact. Kazak and Marvin (1984) found that the size of the support network is not a reflection of its quality or effectiveness. The variable Kazak and Marvin found to be most strongly associated with an effective support network was the density of the connectedness of the members.

Internal Family Resources

Families have their own unique strengths, and resources within the family unit that help them to manage during times of increased stress and pressure such as the experience of raising a child with a developmental disability. These resources may include a strong parental subsystem, individual coping skills, and positive philosophies about life, flexibility, or resourcefulness.

According to Boss' model of family stress (2002), there are two mediating factors, which influence the degree of stress and possible crisis the family experiences throughout the experience of raising a child with a developmental disability. These factors include the *perception* the family has of the diagnosis and the *resources* available to the family to assist them in managing this stressor event.

Family perceptions of the diagnosis vary significantly between families. Seligman and Darling (1989) explain that the experience of learning of a child's diagnosis of disability typically represents a loss for parents of the expectations and dreams they had for the child. Family reactions are often compared to the grief experienced when a family member dies. Foy (1997) and Fortier and Wanlass (1984) describe the stages families experience following the diagnosis as similar to the stage theory of grief. Proponents of the stage theory believe that the grief experienced following a diagnosis of disability may be chronic or re-experienced at different stages of the child's life, as the child does not reach typical developmental milestones. Baxter (1992) studied the relationship between parent perceptions of the appraised significance of the child's disability on the parenting role and child age across three age cohorts (3-5 years, 10-12 years, and17-19 years). Baxter found that the significance of the child's disability on the parenting role as appraised by the parents was increasingly important as a mediator of parenting stress during later childhood to early adolescent years. Baxter does not offer a hypothesis for the increasing salience of parental perceptions of the significance of the child disability as influencing parenting stress increasing between the age cohorts of 3 to 5 years and 10 to 12 years. Baxter explains that further research is required to determine at what point this change occurs between the two age cohorts. One significant life event that occurs between these two groups is the entry into the school system. Further research may assist in developing an understanding of the impact of this transition on perceptions parents have of the child's disability and related changes in parenting stress. The research on perception contributes to the understanding that the variable of child age alone does not demonstrate a consistent correlation with parenting stress. The research suggests that intermediary variables are responsible for differing rates of parenting stress throughout the various life stages of the child.

Recent developments in the field are challenging the traditional assumption that diagnosis of childhood disability necessarily results in a negative reaction. Rather, it is being suggested that for some families the diagnosis of a developmentally disabled child does not create a family crisis and the family is able to adapt effectively (Trute, 1990, 1995; Trute & Hauch, 1988; Trute & Hiebert- Murphy, 2002). Work by Trute and Hiebert- Murphy (2002) examining family adjustment to childhood disability supports the theory that cognitive appraisal, or perception, is a significant mediating factor between the stressor event of the diagnosis and the outcome of crisis or adjustment. Scorgie and Sobsey (2000) interviewed 95 parents of children with disabilities and found that for many of the participants the experience of parenting a child with disabilities was "transformational". The parents described significant positive changes in their lives in the areas of personal growth, improved relationships with others, and changes in philosophical or spiritual values as a result of parenting a child with disabilities.

Research on the parental subsystem and marital cohesion among families of children with disabilities consistently identifies these as critical factors in predicting family adjustment among families of children with disabilities (Abbott & Meredith, 1986; Trute, 1990; Trute & Hauch, 1988). Trute and Hiebert-Murphy (2002) explain that their study "confirmed the importance of the marital relationship in predicting parenting stress, which, in turn, is highly correlated with overall family adjustment" (p. 279).

Family Demographics

Parent gender. Research on gender differences in parental outcomes reports that higher levels of depression have been found among mothers compared to fathers of children with disabilities (Gray & Holden, 1992; Olsson & Hwang, 2001; Trute, 1995). Explanations for the differences in depression between mothers and fathers of children with disabilities are that mothers are more likely than fathers to take on the role of primary caregiver, increasing the parenting demands on the mother and mothers are less likely to have jobs outside the home, which would provide an additional source of identity, gratification, and social contact. Sloper et al. (1991) looked at the outcome variables of stress and satisfaction with life, and found that while child characteristics were strongly associated with outcomes for mothers, the marital relationship and factors external to the family acted as stressors for fathers. Similarly, Kazak and Marvin (1984) found that mothers of children with disabilities experienced levels of stress higher than parents of children without disabilities but fathers of children with disabilities showed levels of stress similar to comparison groups. Studies by Noh et al. (1989) and Dyson (1997), found that fathers as well as mothers of children with disabilities experience higher levels of stress than parents of children without disabilities. Fathers have been studied in smaller numbers and less frequently than mothers of children with disabilities to date. Additional research on fathers may help to explain gender differences among parents of children with disabilities.

Socio-economic status. Cameron and Orr (1989) found that differences in socio-economic status were not relevant in predicting stress among families of children with disabilities. Cameron and Orr suggest that universal health care mitigates the effects of socio-economic status. Research in countries such as the United States finds that socio-economic status is a significant variable affecting stress in families of children with disabilities.

Summary and Overview of the Study

A significant body of literature exists on the topic of families of children with disabilities, however, the relationships between specific unmet needs of the families, child age cohorts at point of entry into the formal service system, and parenting stress have not been examined. Understanding these factors is critical in the effective planning of formal services to support families of young children with disabilities throughout the transitions through the different family life stages. The child characteristic of age has been examined in relation to parenting stress in a number of existing studies, however these studies have not produced consistent results and have not looked at the relationship at the point of entry to the service system. This study looks at the relationship between child age and maternal parenting stress and at differences in parenting stress between mothers of children in different life stages (i.e., infants, pre-school children, and school-aged children) at point of entry into the formal service system. As well, this study looks at reports of unmet needs and parenting stress by mothers in relation to child age at the point of entry to the service system in order to explore the relationships between these variables. Mothers are the focus of this study, as mothers tend to occupy the role of primary caregiver and liaison with service providers for their families (Olsson & Hwang, 2001). The purpose of this study is to begin to address some of the apparent gaps in the literature in order that policy makers and service providers have the information required to develop policies and practices that best meet the needs of families with young children with disabilities entering the service system.

The primary aim of this study is to examine parenting-related stress reported by mothers of children with disabilities at different ages when they enter the community-based service delivery system. Two different ways of conceptualizing the relationship between age of child at entry into the formal service system and maternal stress are explored in the study. Firstly, the age cohort to whom the child belongs at the point of access to the service system may impact maternal stress. To explore this possibility, the responses of mothers of children within three distinct age cohorts are examined: infants (6-18 months), pre-school children (19-60 months) and school-age children (61-144 months). The cohorts represent three distinct stages in the child-parent relationship and represent time periods when distinct (and differing) services are available to support children and families. The purpose of this form of enquiry is to determine whether differences in maternal stress are found as a result of factors related to the differences in child stage at point of entry into the formal service system.

A second way of conceptualizing the relationship between maternal stress and age of child at entry into the service system is as a correlational relationship. Age of child at entry into the service system is generally determined by when the diagnosis occurs, as a diagnosis is part of the eligibility criteria for most services. Often families experience challenges associated with raising a child with a disability prior to receiving an official diagnosis, thus they do not have access to much-needed services. The older the child at entry into the service system, the longer the needs have potentially gone unmet resulting in increased maternal stress. There are also families who receive a diagnosis earlier but for whatever reasons are not referred to the service system.

An additional aim of the study is to examine the types of needs reported at entry to services in order to explore whether there are differences in the needs reported by mothers of children in different age cohorts.

Research Questions and Hypotheses

Primary research questions: Do levels of maternal stress and reported needs differ between the mothers of children in three age cohorts: infants (6-18 months), pre-school children (19-60 months), and school-age children (61-144 months) at entry into the service system? Is there a positive correlation between maternal stress and age of child at admission to the formal service system?

Hypothesis 1: Stress levels will be higher among mothers of children in the pre-school group compared to the infant group and higher among mothers of children in the school-age group compared to the pre-school group.

Hypothesis 2: On the basis of research suggesting that factors such as delayed diagnosis and lack of formal supports are related to an increase in parenting stress, it is predicted that a positive correlation will be found between stress reported by mothers and age of children upon entry into the formal service system.

Exploratory research questions: Do differences in reported needs appear in the data collected from mothers of children with developmental disabilities of different age levels (infant, pre-school and school-aged as defined above) at point of entry into the formal service system? Are any specific needs significantly associated with increased levels of maternal stress?

Method

The data for this study were collected as part of a larger project, The Family Strengths in Childhood Disability Research Project (FSCD). As outlined on the study's web page www.familystrengths.ca (2000) the aim of the FSCD is to:

> track and assess the factors that facilitate or hinder the movement of Manitoba services for children with disabilities and their family members from an individual orientation to a family centered one. As well, family assessment protocols, which include both standardized empirical measures and structured parent interviews, will be evaluated for measurement reliability and predictive validity.

Parents of children with developmental disabilities were followed from the period of six months following the child's entry into the formal service system until twelve months following the initial data collection. Participants included a sample of families from two Manitoba health regions (one largely urban and the other mixed urban and rural). Families were eligible for the study when they qualified for care from Children's Special Services, a provincial agency providing a case coordinator for families with a child with a developmental disability. The parents were invited to participate by their case coordinator who obtained written consent to release the contact information of those parents interested in participating in the study. The project interviewer, prior to the collection of further information, obtained a second written consent.

The sample was screened to ensure that their children were under the age of twelve years, had a developmental disability, and had not been open to the program at any other time or in any other region. The sample was also screened to ensure that the parents could speak and had basic reading skills in English. As reported by Trute and Hiebert-Murphy (2005), Time 1 (T1) data was collected from 106 mothers and 70 fathers from 111 families over a ten-month period from October 2000 to July 2001, six months following the entry to the service system, with a response rate of 74%. Time 2 (T2) data was collected from 103 mothers and 55 fathers from 103 families, one year following T1 participation, with a response rate of 68%. In total, the parents of 111 children participated in the study.

The first phase of data collection included a 1 ½ -hour visit by an interviewer to the participants' homes to administer a series of questionnaires. A smaller sample was selected to participate in a qualitative interview in addition to the questionnaires. The second phase of data collection involved the completion of measures, during a 1 ½ -hour visit. The same smaller sample of families was asked to participate in the qualitative interviews for the T2 phase. Fifty-six qualitative interviews were conducted during T1 and 60 parent interviews were conducted during T2. The participants who completed the quantitative measures were given an honorarium of $25 for their participation. The participants who also participated in the qualitative interview received a $50 honorarium. In addition to the data collected from the families, 44 child files were reviewed, and data was collected from case coordinators, supervisors and key informants in the disability field.

Procedure

The source of the data for this study is the archive of quantitative data completed by 106 mothers who participated in the first phase (T1) of the FSCD. The measures used in the study are the Parenting Stress Index, short form (PSI-SF; Abidin, 1995) and the Family Needs Survey (FNS; Bailey & Simeonsson, 1988). This data set contains no identifying information.

Measures

Parenting Stress

Parenting stress is assessed using the Parenting Stress Index, short form (PSI-SF; Abidin, 1995). The PSI-SF is a 36-item parent self-report measure "designed to measure stress in the parent-child system and identify those families most in need of follow-up services" (Reitman, Currier, & Stickle, 2002, pp. 387). The PSI-SF is composed of three subscales including Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. Abidin reports that the PSI-SF was found to have both test-retest reliability and internal consistency. Coefficient alpha is calculated to be very strong at the level of .91 for the scale of Total Stress based on the normative sample of 800 subjects. The coefficient alpha is also found to be strong for the sub-scales at .87 for Parental Distress (PD), .85 for Difficult Child (DC), and .80 for Parent-Child Dysfunctional Interaction (P-CDI). The reason for the slightly weaker alpha for P-CDI is that it is composed of items from both the Child Domain and the Parent Domain of the full length PSI. The PSI-SF is not supported by an independent body of research supporting its validity, however, "because it is a direct derivative of the full-length PSI, it is likely that it will share in the validity of the full length PSI" (Abidin, p. 61). The study sample is similar to the standardization sample for the PSI-SF described by Abidin (1995) in which the women were 87% Caucasian and 88% married. This study examines the scores on each of the three subscales within the PSI-SF in order to understand participants' parenting stress.

Family Needs

The Family Needs Survey (FNS; Bailey & Simeonsson, 1988) is a 35-item parent survey designed as a tool for the assessment of the needs of families with young children with developmental disabilities. The items in the scale are grouped into seven categories including needs for family and social support, needs for information, help explaining child's condition to others, community services, financial needs, child care and professional support. The rating system is from 1 to 3, where 1 represents the statement "I definitely do not need help with this", 2 represents "Not sure", and 3 represents "I definitely need help with this". The participants in the initial field-testing of the scale (Bailey & Simeonsson, 1988) included 34 two-parent families participating in home-based infant intervention programs. The average age of the infants was 14 months. Approximately 85% of the children were Caucasian and 15% belonged to a visible minority group. Fourty-seven of the families were described as falling within a low SES. Responses of mothers and fathers were analyzed separately by calculating the percentages of each of the responses for each of the 35 items on the scale. Twenty of the families completed the instrument a second time six months following the first so as to assess stability of responses. Test-retest correlations for total scores were moderate for mothers at .67 ($p < .001$) and high for fathers at .81 ($p < .001$). These test-retest scores may in fact reflect that some of the needs initially identified were no longer unmet at the retest rather than demonstrating a weakness of the scale. Bailey and Simeonsson recognize a limitation of the measure to be that it only reflects those needs that the family is able or willing to identify. Further assessment needs to be completed to determine whether additional needs exist. In the present study the FNS is scored by looking at the number of unmet needs identified by the respondents within each of the need categories.

Results

Participant Characteristics

The average age of the 106 women in the study was 34 years (*SD* = 7.07) with women ranging in age from 19 to 65 years. Most of the mothers (86%) in the sample identified themselves as Canadians of European descent. Five percent identified themselves as Aboriginal Canadians and 9% identified themselves as visible minorities. The number of children in the home ranged from one to six with the mean number of children in the home being 2.4 (*SD* = 1.21). As shown in Table 1 the majority of women (80%) were living in partner relationships. Table 2 shows that approximately half of the women (51%) were engaged in paid employment on a full-time or part-time basis. Ninety-one percent of the women graduated from high school with 30% continuing on to postsecondary education (see Table 3).

The children with developmental disabilities that were the focus of the study were an average of four years or 49.92 months (*SD* = 34.54) with a range of 5 months to 144 months. Sixty-seven percent of the children were male and 33% were female. All of the children had a formal diagnosis of developmental disability. As reflected in Table 4, based on parental reports, 33% of the children had a diagnosis of DD-NOS and 40% had a diagnosis of an autism spectrum disorder. Other diagnoses included cerebral palsey, Down syndrome and DD- genetic or metabolic.

Data Screening

Prior to the analysis of the data, all variables were checked for accuracy of data entry and missing values. The minimum and maximum values, means, and standard deviations of the variables were inspected for plausibility. The data set contained minimal amounts of missing data. Missing values on descriptive variables were left missing and were deleted from analyses. The Family Needs Survey was interpreted conservatively with missing data coded as “no”.

The parenting stress and family needs variables were examined to assess the fit between their distributions and the assumptions of normality. The values for skewness and kurtosis for the PSI-SF were less than one, indicating that the variable was normally distributed.

For the FNS, analysis of each of the subscales resulted in values of less than one for both skewness and kurtosis with one exception: the statistic for skewness for the subscale of the reported need for professional help was 1.24, which is still considered acceptable. Given these findings, it was concluded that the variables met the assumptions of normality.

Internal Consistency

The internal consistency of each scale and their subscales was considered by examining Cronbach's alpha. With a total scale alpha level of .82 the Family Needs Scale was found to have good overall internal consistency. Internal consistency for each of the subscales as shown in table 5 is strongest on the subscales of information (.80), and family and social support (.82). The alpha

Table 1

Marital Status of Mothers (N = 105)

Marital Status	*N*	%
Married	75	72
Separated or divorced	8	7
Living as married	9	8
Never married	12	11
Widowed	1	1

Table 2

Employment Status of Mothers (N = 105)

Employment	*N*	%
Full-time employment	40	38
Part-time employment	14	13
Full-time homemakers	34	33
Unemployed seeking work	4	4
Disabled, unable to work	2	2
Self-employed	3	3
Retired	1	1
Student	2	2
Other	5	5

Table 3

Highest Level of Education Completed by Mothers (N = 105)

Education	*N*	%
Completed grade 8 or less	2	2
Some high school education	7	7
High school graduates	61	61
Some postsecondary education	30	30

Table 4

Primary Diagnosis Reported by Mothers (N = 111)

Diagnosis	*N*	%
DD- Not Otherwise Specified	36	33
Autism	20	19
Pervasive Developmental Delay	14	12
Cerebral Palsey	12	10
Asperger	11	9
Down syndrome	9	8
DD- Genetic or Metabolic	1	1
DD- other	8	7

levels on the subscales of childcare (.51), community services (.41), and professional support (.55) all indicate low reliability. This may be a reflection of the number of items in each of these subscales as each contains only three items.

At .94 the internal consistency of the Parenting Stress index was found to be high. The subscales also scored high on levels of reliability with an alpha score of .92 for the child related stress subscale, .83 for the parent-child dysfunctional relationship subscale, and an alpha of .89 for the parental stress subscale. None of the respondents were found to be responding defensively to the Parenting Stress Index as all of the participants scored above the cutoff score of ten on the test for defensive responses.

Total stress mean for the sample (*M* = 90.9) was higher than the mean reported for the PSI standardization sample (*M* = 71.0). Fifty-one percent of mothers scored at or above 90 on the PSI-SF total scale, the clinically significant cutoff level. This suggests that a majority of mothers in this sample were experiencing high levels of parenting stress.

Table 5

Alpha Levels for Family Needs Survey Subscales

Subscale	∝
Information	.80
Family and social support	.82
Financial support	.73
Help explain	.75
Child care	.51
Professional help	.55
Community services	.41

Tests of Hypotheses

Hypothesis 1: Parenting Stress Among Mothers of Infants, Pre-school Children, and School-aged Children

The breakdown of participants in this study, into three child age cohorts is done according to type of services for which they are eligible. The infant group, for example was set at 6 to 18 months as the youngest children were eligible to participate in the research 6 months following the initial referral to services and generally children do not become eligible for pre-school services until they reach 18 months within the region being studied. Children 19 to 60 months are generally eligible for pre-school and early intervention services thus they were grouped separately from children 60 to 144 months who become eligible for services through the education system. Furthermore, these age groups are typically associated with distinct developmental milestones for the children and have different impacts on the roles of the parents. To test hypothesis 1, that differences in maternal stress would be found among the three age cohorts, an ANOVA was conducted. Scheffe's method was employed to determine the direction and significance of the differences between the three groups. Scheffe's method was selected, as it is a conservative post hoc test designed to determine where and to what degree differences exist between groups (*NIST/SEMATECH*, 2006).

No differences were found between the mothers of children in the three age cohorts on the total PSI-SF scale at point of entry, $F(2, 101) = 2.32$, $p = .10$. A significant difference was found however in the PSI-SF scores on the subscale of child related stress, $F(2, 101) = 4.90$, $p = .01$. Post hoc comparisons of the means using the Scheffé method indicates that the difference exists between the PSI scores of the mothers in the infant child age category ($M = 27.19$) and the pre-school ($M = 36.62$) and school-aged groups ($M = 35.23$) with higher PSI scores among the mothers of children in the older two age groups. There is not a significant difference between PSI scores of mothers in the pre-school and school-aged child age categories. There were no significant differences between the groups on the other subscales of the PSI-SF.

Hypothesis 2: The Relationship between Child Age and Maternal Parenting Stress

Pearson's correlation was used to test hypothesis 2 that predicted that a positive correlation exists between child age at entry into the formal service system and maternal stress. As predicted, a positive correlation was found between age of child at entry into the formal service system and maternal PSI scores, $r(102) = .21$, $p < .05$. No correlations were found between the child's age at entry to services and the parent-child dysfunction or parental distress subscales of the PSI. The child related stress subscale was found to be correlated to child age, $r(102) = .26$, $p < .01$.

Exploratory Research Questions: Family Needs Reported by Mothers of Infants, Pre-school Children, and School-aged Children

Correlational analyses between child age and needs (see Table 6) found a negative correlation between child age and financial need, $r(98) = -$

.27, *p* = .007, and childcare needs, *r* (97) = -.29, *p* = .003 (to control for type one error Bonferroni's correction was used to set an alpha level of .007). ANOVA was used to test whether significant differences in number of unmet needs exist between the mothers of the children in each of the three age cohorts. As shown in Table 7, no significant differences between groups were found between the child age categories on the number of unmet needs on the FNS subsections (an alpha level of .007 was set using Bonferroni's correction). Differences between the groups on financial needs, *F*(2, 97) = 3.80, *p* = .03 and childcare needs, *F*(2, 96) = 4.76, *p* = .01 approached significance with mothers in the infant group reporting more financial needs (*M* = 2.93) and childcare needs (*M* = 1.25) than mothers of pre-school children (*M* = 2.14 for financial needs and *M* = .91 for childcare needs) and school-aged children (*M* = 1.21 for financial needs and *M* = .33 for childcare needs).

To understand which types of unmet needs are associated with increased parenting stress, Pearson's correlation analyses were conducted between PSI scores and each of the subgroups of needs. As shown in Table 8, correlations were found between total parenting stress and the needs subscales of information, *r* (96) = .293, *p* = .003, family and social support, *r* (94) = .324, *p* = .001, help explaining, *r* (95) = .373, *p* = .000, and professional help *r* (97) = .332, *p* = .001 (Bonferroni's correction was used to set the alpha at .007). To better understand the correlations between the subsections and the PSI scores, the specific needs of the subsections in which correlations were found, were analyzed using Pearson's correlation. Table 9 reflects which individual needs, on the subscales that were found to be correlated to PSI scores, are correlated to PSI scores. Given the exploratory nature of these analyses, Bonferroni's correction was used to control for type one error (the alpha level was set at .0018). Correlations were found between PSI scores and the need for information on "how to handle child's behavior", *r* (100) = .403, *p* = .000, and "child's condition or disability", *r* (100) = .337, *p* = .001, the need for support on "family discuss[ing] problems and solutions", *r* (98) = .321, *p* = .001, and the need for help "respond[ing] to friends and neighbours", *r* (99) = .380, *p* = .000.

Table 6

Correlation Analyses Between Child Age and Needs Subscales

Subscale	*r*	*p*
Information	-.034	.735
Family and social support	-.069	.503
Financial support	-.269*	.007
Help explain	-.049	.630
Child care	-.294*	.003
Professional help	.024	.811
Community services	-.061	.546

*$p < .007$

Table 7

ANOVA for Needs Subscales by Child Age Categories

Category of Need	*F*	*df*	*p*
Information	0.57	2, 96	.57
Family and social support	0.52	2, 94	.60
Financial support	3.80	2, 97	.03
Help explain	0.13	2, 95	.88
Child care	4.76	2, 96	.01
Professional help	0.30	2, 97	.74
Community services	0.33	2, 97	.72

Table 8

Correlation Analyses Between PSI Scores and Needs Subscales

Subscale	*r*	*p*
Information	.293*	.003
Family and social support	.324*	.001
Financial support	.089	.381
Help explain	.373*	.000
Child care	.157	.122
Professional help	.332*	.001
Community services	.119	.239

*$p < .007$

Table 9

Correlation Analyses Between PSI Scores and Identified Needs

Need	*r*	*p*
Information		
How children grow and develop	.072	.475
How to play or talk with child	.179	.074
How to teach child	.195	.051
How to handle child's behavior	.403*	.000
Child's condition or disability	.337*	.001
Services presently available	.136	.181
Services for parents	.176	.078
Child services in future	-.043	.668
Family and social support		
Talking with someone in family	.013	.902
Friends to talk to	.085	.402
More time for self	.272	.006
Help spouse accept	.237	.017
Family discuss problems and solutions	.321*	.001
Family support during difficult times	.285	.004
Deciding who does chores and childcare	.168	.095
Family deciding and doing recreation	.127	.210
Skills to use social support	.176	.082

Table 8 con't

Need	*r*	*p*
Help explaining		
Explain to parents and spouse parents	.206	.040
Explain to child's siblings	.298	.003
Respond to friends and neighbours	.380*	.000
Explain to other children	.292	.003
Reading materials	.177	.079
Child care		
Find babysitters or respite care	.306	.002
Day care or pre-school	-.056	.583
Nursery during religious services	.086	.396
Professional help		
Minister, priest, rabbi	.245	.014
Meet with counselor	.212	.033
Talk with teacher or child therapist	.253	.012

*$p < .0018$

Discussion

A primary finding of this study was the relationship between child age and maternal parenting stress at point of entry to the service system. A weak positive correlation was found between child age (6-144 months) and maternal stress. Mothers of infants were found to report lower parenting stress than mothers of pre-school and school-aged children. While no previous research was found that examines the relationship between child age at point of entry and parenting stress, the research on the relationship between parenting stress and child age has been inconclusive to date. Some studies report findings that are contradictory to the findings of this study. That is, some research reports that parents of infants with disabilities experience higher levels of parenting stress than parents of older children with disabilities (Beckman,1991; Dumas et al. ,1991; Baxter et al.,1995; Trute,1995). Other research finds that child age child is unrelated to parenting stress (Boyce & Behl, 1991; Cameron & Orr, 1989; Flint & Wood, 1989).

The findings of this study suggest that age at entry to formal services may be a critical variable in understanding parenting stress. The reason for higher levels of parenting stress of mothers of older children at point of entry to the service system is not clear, however, there are several plausible explanations. One explanation for this relationship may be the differences in the experience of receiving a diagnosis and accessing services between mothers of children in the different age cohorts. Research by Avdi et al. (2000) suggests that the experience of believing that one's child may have a problem but not having a diagnosis can be a very stressful experience for parents. Parents of children in the older age cohorts (pre-school and school-age) are more likely to have had the experience described by Avdi et al., of suspecting that their child has a disability but not having confirmation or any information about what the disability may be or services available. The older the child is when the family accesses the formal service system, the longer parents have potentially endured this stressful period.

Another plausible explanation for a relationship between child age and parenting stress at entry to formal services is the difference in the impact of child behavior on parenting stress. This is supported by the findings of this study as the differences in parenting stress between the child age groups, as reflected in PSI scores, were found to be specifically associated with "child related" parenting stress. Child related parenting stress refers to the behavioral characteristics or self-regulatory processes of the child that affect the parent's ability to manage him/her (Abidin, 1995). The literature on parenting stress associated with parenting children with disabilities points to behavioral issues as the most significant source of stress for this group (Beckman, 1983; Bouma & Schweitzer, 1990; Boyce & Behl, 1991; Dumas, et al., 1991). Maternal reports of "child related" parenting stress at point of entry into the formal service system were found to increase significantly between the child age groups of 0 to 18 months and 19 to 60 months. As children grow older behavioral challenges related to a disability become more apparent. The child's peers develop the ability to self-regulate whereas children with disabilities may be delayed in this area. Furthermore, behavioral challenges become increasingly difficult to manage as a child increases in size and develops increased mobility.

It is also plausible that the greater parenting stress experienced by mothers of pre-school and school-age children is related to greater unmet needs in this group compared to mothers of infants. Such differences were not found in this study however a different measure of needs may yield different results. Further research is required to better understand the specific reasons for the differences between the groups.

Any of the aforementioned factors may potentially cause parenting stress to be higher among mothers of pre-school and school-aged children at point of access to formal services than mothers of infants with disabilities. Given the relative weakness of the correlation, caution should be taken in the interpretation of the findings. Further research needs to be conducted to develop a better understanding of the impact of delayed entry to the service system on families.

If a delay in access to services is responsible for parenting stress the implications for practice must be considered. Most importantly, service providers would need to be aware of the potential for higher levels of parenting stress among parents of pre-school and school-age children entering the service system. Service providers would need to work to shorten the length of time families wait to access services, consider changing eligibility criteria for services to include children who demonstrate certain symptoms but may not yet have a formal diagnosis, and increase resources to services in order to ensure availability of services for families and children once they have entered the service system. Providing timely access to services for children entering the service system may help to prevent crisis and potentially the need for unplanned placement out of the family home.

A negative outcome should not be assumed because of the presence of stress. Boss' model of stress highlights that both positive and negative events can be sources of stress. The outcome is determined by how the stress is managed. With a positive perception of the experience of parenting a child with disabilities and the resources required to meet the needs of the family, the stress can be managed effectively and not necessarily result in a negative outcome. Unfortunately, measures such as the PSI assess aspects of parenting that are predetermined to be considered negative. They do not assess parent's perceptions nor do they consider positive aspects of parenting.

Another finding of the study was that the mean total parenting stress in the sample was found to be above the clinically significant cutoff level for parenting stress. This finding is consistent with the findings in existing literature that reports that parents of children with disabilities experience higher levels of parenting stress than those of the general population of parents (Dyson, 1997; Gowen, Johnson-Martin, Goldman, & Appelbaum, 1994; Wilton & Renault, 1986). This study confirms that a high level of parenting stress exists at point of entry to the service delivery system. The literature on increased stress during the experience of diagnosis (Baxter, Cummins, & Polak, 1995; Seligman & Darling, 1989) may help to explain why parenting stress is elevated at this point in families' lives, as typically access to services follows diagnosis. It is important for professionals working with or planning services for families of children with developmental disabilities entering the service system recognize that these families commonly experience elevated levels of parenting stress. Services should be designed to accommodate the numbers of families entering the system to ensure availability of resources. More energy should be focused on working with families early in their involvement in the services system to help them to manage with the stress associated with this time in their lives.

An examination of the needs identified by the mothers in this study provides further insight into how services should be designed to meet the needs of mothers entering the service system. Analyses conducted to examine the relationship between child age groups, parenting stress, and needs found greater identification of unmet needs in the areas of financial support and childcare for families with younger children. However, this study found that need for support in these areas was not related to elevated parenting stress at point of access to the service system as the identification of need on these subscales was not found to be correlated to parenting stress. A measure of acuity of need may provide greater insight into why some needs are associated with parenting stress whereas others are not. A possible explanation for the greater identification of financial and childcare needs among parents of younger children may be that these are areas of concern among parents of younger children without disabilities as well and that these concerns resolve themselves over time. Further research would be required to determine whether this might be the case. The examination of the relationship between needs and parenting stress found that the unmet need for information on the condition or disability is associated with increased parenting stress. This finding is consistent with literature on the needs of parents to obtain information following the diagnosis of their child. Nissenbaum, Tollefson, and Reese (2002) purport that the most useful support professionals can offer families during the time of diagnosis is clear and timely information regarding both the diagnosis and the prognosis. Best practice policies should include the provision of information for all parents on their child's condition or disability following diagnosis. The other need for information found to be correlated with increased parenting stress is information on how to handle the child's difficult behavior. This is consistent with the finding of the correlation between parenting stress and children with difficult to manage behavior. Parents identifying the need for information on how to handle a child's difficult behavior are likely to be experiencing difficulty with their child's behavior. Literature clearly reflects that difficult child behavior is a source of stress for parents (Beckman, 1983; Bouma & Schweitzer, 1990; Boyce & Behl, 1991; Dumas et al., 1991).

Another need found to be correlated to parenting stress is support from family to discuss problems and solutions. Literature supports the salience of the informal support provided by family and friends for parents in managing the stressors associated with parenting children with disabilities (Abbot & Meredith, 1986; Judge, 1998; Kazak & Marvin, 1984; Trute & Hauch, 1988). It is important for professionals to be aware of the impact of the informal support provided by family and friends on parents of children with disabilities to be able to effectively evaluate and assess the needs of parents in this area.

The final need on the FNS found to be correlated with parenting stress is help responding to the enquiries of friends and neighbours regarding the child's condition. Little research is available on the experience of communicating with friends and neighbours regarding the condition or disability of the child as a stressor for parents. Qualitative research would be helpful in developing an understanding about why this is a source of stress for mothers, whether this continues to be a source of stress throughout the child's life, whether this is a source of stress for fathers or siblings as well, and what support might help to address this stressor.

The examination of needs as reported by parents is critical in developing services that provide parents with the resources they require to manage stressors. When parents are equipped with the resources they require to manage the stressors associated with parenting a child with disabilities they are better able to maintain stability within the family unit (Gallagher, Beckman, & Cross, 1983).

Unfortunately the Family Needs Scale does not measure acuity of need. It does not provide an assessment of the parent's rating of the degree of need or impact of having the need remain unmet. A measure of acuity of need may produce different findings than simply measuring frequency of reports of unmet needs. Other researchers investigating needs of this population, such as Redmond and Richardson (2003) and Mitchell and Sloper (2002), have employed a qualitative method to learn about needs on a more in-depth level, however this research is descriptive of the needs expressed by parents for service delivery style (i.e., ideal services described as consistent, reliable, and home-based), rather than needs for types of services.

Further limitations to the use of the FNS in this research are the self-report nature of the measure and the limited scope of the questions. Because the FNS is a self-report measure, responses are limited to those needs that parents are willing and able to identify. The measure was designed originally as an assessment tool for an early intervention program, thus the questions are geared towards the needs of parents of younger children. Parents of older children may experience needs not included on the scale.

Conclusion

Findings of this study confirm that a relationship exists between child age and maternal stress. Further research is required in order to develop a more thorough understanding of these variables to aid policymakers and service providers in designing services to best meet the needs of families of children with developmental disabilities.

A longitudinal study tracking changes in stress over time would provide insight into what factors are associated with changes in levels of stress, and whether any patterns associated with diagnosis and accessing services emerge. Additional research on the service needs of families of children entering the service system is required in order to ensure appropriate services are available. A qualitative study would be helpful to develop an understanding of the needs of parents of older children with disabilities and how needs differ between families of children in different age cohorts or life stages. Another suggestion for future research is a study comparing results of the population in this study to results of the same measures with a matched sample, with the independent variable being amount of time since entry to the formal service system. This would highlight whether the results of this study are common to all mothers of children with disabilities within the age categories examined or whether differences exist depending upon amount of time services have been available.

It is important for research to continue to focus on stressors associated with parenting a child with a disability in order to be able to better design services to address the needs of the families who require support. Not all families of children with disabilities require or desire formal services. By being able to identify the families most likely to require formal services, resources can be better directed to the families who need them most.

References

Abbot, D. A., & Meredith, W. H. (1986). Strengths of parents with retarded children. *Family Relations, 35,* 371-375.

Abelson, G. A. (1999). Respite care needs of parents of children with developmental disabilities. *Focus on Autism & Other Developmental Disabilities, 14,* 96-101.

Abidin, R. R. (1995). Parenting Stress Index Third Edition professional manual. Odessa, FL: Psychological Assessment Resources, Inc.

Arnold, L. E. (Ed.). (1978). *Helping parents help their children.* New York: Brunner/Mazel.

Arcia, E., Fernandez, M. C., Jaquez, M., Castillo, H., & Ruiz, M. (2004). Modes of entry into services for young children with disruptive behaviors. *Qualitative Health Research, 14,* 1211-1226.

Avdi, E., Griffin, C., & Brough, S. (2000). Parents' constructions of the 'problem' during assessment and diagnosis of their child for an autistic spectrum disorder. *Journal of Health Psychology, 5*, 241-254.

Bailey, D. B., & Simeonsson, R. J. (1988). Assessing needs of families with handicapped infants. *The Journal of Special Education, 22,* 117-127.

Baxter, C. (1992). Appraised significance of intellectual disability for parents of children in three age cohorts. *Journal of Intellectual Disability Research, 36,* 519-529.

Baxter, C, Cummins, R. A., & Polak, S. (1995). A longitudinal study of parental stress and support: From diagnosis of disability to leaving school.

International Journal of Disability, Development and Education, 42, 125-136.

Beavers, J., Hampson, R. B., Hulgus, Y. F., & Beavers, R. W. (1986). Coping in families with a retarded child. *Family Process, 25,* 365-377.

Beck, A. T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4,* 561-571.

Beckman, P. J. (1995). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation, 95,* 585-595.

Beckman, P. J. (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.

Beckman, P. J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. *American Journal of Mental Deficiency, 88,* 150-156.

Beckman, P. J., & Boyes, G. B. (1993). *Deciphering the system: A guide for families of young children with disabilities.* Brookline Books: Cambridge.

Boss, P. (2002). *Family stress management: A contextual approach, 2nd ed.* Thousand Oaks: Sage.

Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46,* 722-730.

Boyce, G. C., & Behl, D. (1991). Child characteristics, family demographics and family processes: Their effects on the stress experienced by families of children with disabilities. *Counselling Psychology Quarterly, 4,* 273-289.

Brett, J. (2004). The journey to accepting support: How parents of profoundly disabled children experience support in their lives. *Pediatric Nursing, 16,* 14-18.

Buehler, C. (2001). Adjustment. In J. Touliatos, B. F. Perlmutter & M. A. Straus (Eds.), *Handbook of family measurement techniques* (pp. 247-255), Thousand Oaks, CA: Sage.

Byrne, E., & Cunningham, C. (1985). The effects of mentally handicapped children on families- A conceptual review. *Journal of Child Psychology and Psychiatry, 26*, 847-864.

Cameron, S., & Orr, R. R. (1989). Stress in families of school-aged children with delayed mental development. *Canadian Journal of Rehabilitation, 2,* 137-144.

Crinc, K. A., Friedrich, W. N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency, 88,* 125-138.

Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality, 2,* 97-110.

Dunst, C. J., Jenkins, V., & Trivette, C. M. (1984). Family support scale: Reliability and validity. *Wellness Perspectives, 1,* 45-52.

Dyson, L. 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.

Eyberg, S. M., & Ross, A. W. (1978). Assessment of child behavior problems: The validation of a new inventory. *Journal of Clinical Child Psychology,* 113-116.

Firth, M. (1982). How good is professional support following a diagnosis of mental handicap? *Health Visitor, 55,* 215-220.

Flynt, S. W., & Wood, T. A. (1989). Stress and coping of mothers of children with moderate mental retardation. *American Journal on Mental Retardation, 94,* 278-283.

Fortier, L. M., & Wanlass, R. L. (1984). Family crisis following the diagnosis of a handicapped child. *Family Relations, 33*, 13-24.

Fost, N. (1981). Counseling families who have a child with a severe congenital abnormality. *Pediatrics, 67,* 321-325.

Foy, E. (1997). Parental grieving of childhood disability: A rural perspective. *Australian Social Work, 50*, 39-44.

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

Gowen, J. W., Johnson-Martin, N., Goldman, B. D., & Appelbaum, M. (1994). Feelings of depression and parenting competence of mothers of handicapped and non-handicapped infants: A longitudinal study. *American Journal on Mental Retardation, 94,* 259-271.

Gray, D. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability, 27,* 215-222.

Gray, D., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities, 18,* 83-93.

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29,* 1-17.

Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency, 80,* 431-436.

Jedlicka-Kohler, I., Gotz, M., & Eichler, I. (1996). Parents' recollection of the initial communication of the diagnosis of cystic fibrosis. *Pediatrics, 97,* 204-210.

Judge, S. L. (1998). Parental coping strategies and strengths in families of young children with disabilities. *Family Relations, 47,* 262-268.

Kazak, A. E., & Marvin, R. S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations, 33,* 67-77.

Maijala, H., Astedt-Kurki, P., Paavilainen, E., & Vaisanen, L. (2003). Interaction between caregivers and families expecting a malformed child. *Journal of Advanced Nursing, 42,* 37-46.

McCubbin, H. I., & Figley, C. R. (Eds.). (1983). *Stress and the family* (Vols. 1&2). New York: Brunner/Mazel.

McKinney, B., & Peterson, R. A. (1987). Predictors of stress in parents of developmentally disabled children. *Journal of Pediatric Psychology, 12, 133-149.*

Mickelson, K. D., Wroble, M., & Helgeson, V. S. (1999). "Why my child?": Parental attributions for children's special needs. *Journal of Applied Social Psychology, 29,* 1263-1292.

Mitchell, W., & Sloper, P. (2002). Information that supports rather than alienates families with disabled children: Developing a model of good practice. *Health and Social Care in the Community, 10,* 74-81.

Newman, B. A. (2000). The challenges of parenting infants and young children. In P. C. McKendry & S. J. Price (Eds.), *Families and change: Coping with stressful events* (pp. 45-70), Thousand Oaks, CA: Sage.

Nissenbaum, M. S., Tollefson, N., & Reese, R. M. (2002). The interpretive conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities, 17*, 30-44.

NIST/SEMATECH e-Handbook of Statistical Methods. Retreived June 20, 2006 from http://www.itl.nist.gov/div898/handbook/prc/section4/prc472.htm

Noh, S., Dumas, J. E., Wolf, L. C., & Fisman, S. N. (1989). Delineating sources of stress in parents of exceptional children. *Family Relations, 38,* 456-461.

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research, 45,* 535-543.

Olsson, M. B., & Hwang, C. P. (2002). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research, 46,* 548-559.

Quine, L., & Pahl, J. (1987). First diagnosis of a severe handicap: A study of parental reactions. *Developmental Medicine and Child Neurology, 29,* 232-240.

Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. (2004). Meeting the needs of parents around the time of diagnosis of disability among their children: Evaluation of a novel program for information, support, and liaison by key workers. *Pediatrics, 114,* 477-481.

Redmond, B., & Richardson, V. (2003). Just getting on with it: Exploring service needs of mothers who care for young children with severe/ profound and life-threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16,* 205-218.

Reitman, D., Currier, R. O., & Stickle, T. R. (2002). A critical evaluation of the Parenting Stress Index- Short Form (PSI-SF) in a head start population. *Journal of Clinical Child and Adolescent Psychology, 31,* 384-392.

Rodrigue, J. R., Morgan, S. B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19,* 371-379.

Sawin, K. J., & Harrigan, M. P. (1995). *Measures of family functioning for research and practice.* New York: Springer Publishing Company.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children with disabilities. *Mental Retardation, 38*, 195-206.

Seligman, M., & Darling, R. B. (1989). *Ordinary families, special children: A systems approach to childhood disability.* New York: The Guilford Press.

Siegel, B. (1996). *The world of the autistic child: Understanding and treating autistic spectrum disorders.* New York: Oxford University Press.

Skinner, H. A., Steinhauer, P. D., & Santa-Barbara, J. (1983). The family assessment measure. *Canadian Journal of Community Mental Health, 2,* 91-105.

Skinner, H. A., Steinhauer, P. D., & Sitarenios, G. (2000). Family assessment measure (FAM) and process model of family functioning. *Journal of Family Therapy, 22,* 190-210.

Sloper, P., Knussen, C., Turner, S., & Cunningham, C. (1991). Factors related to stress and satisfaction with life in families of children with Down's syndrome. *Journal of Child Psychology and Psychiatry, 32,* 655-676.

Tidmarsh, L., & Volkmar, F. R. (2003). Diagnosis and epidemiology of autism spectrum disorders. *Canadian Journal of Psychiatry, 48,* 517-525.

Trute, B. (1990). Child and parent predictors of family adjustment in households containing young developmentally disabled children. *Family Relations, 39*, 292-297.

Trute, B. (1995). Gender differences in the psychological adjustment of parents of young, developmentally disabled children. *Journal of Child Psychology and Psychiatry, 36*, 1223-1242.

Trute, B., & Hauch, C. (1988). Building on family strength: A study of families with positive adjustment to the birth of a developmentally disabled child. *Journal of Marital and Family Therapy, 14*, 185-193.

Trute, B., & Hiebert-Murphy, D. (2002). Family adjustment to childhood developmental disability: A measure of parent appraisal of family impacts. *Journal of Pediatric Psychology, 27*, 271-280.

Trute,B., & Hiebert-Murphy, D. (2005). Predicting family adjustment and parenting stress in childhood disability services using brief assessment tools. *Journal of Intellectual and Developmental Disability, 30,* 217-225.

Trute, B., Hiebert-Murphy, D., & Wright, A. (n.d.). *Family Strengths in Childhood Disability Project: Study methodology and results.* Retrieved 10/10/2005. www.familystrengths.ca.

Wikler, L. (1981). Chronic stresses of families of mentally retarded children. *Family Relations, 30,* 281-288.

Wilton, K. (1986). Stress levels in families with intellectually handicapped pre-school children and families with nonhandicapped pre-school children. *Journal of Mental Deficiency Research, 30,* 163-169.