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**Maternal Perceptions of Support from Professionals and Daily Care-Giving Burden as  
Determinants of Distress in Mothers of Children with Developmental Disabilities**

**by**

**Lena Janine Freeman**

**A Thesis  
Submitted to the Faculty of Graduate Studies and Research  
through the Department of Psychology  
in Partial Fulfilment of the Requirements for  
the Degree of Master of Arts at the  
University of Windsor**

**Windsor, Ontario, Canada**

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## ABSTRACT

This study investigated whether the current movement toward family-centred health care service delivery effectively addresses the distress associated with the daily care-giving burden experienced by mothers of children with developmental disabilities. Participants were 37 mothers of children with developmental disabilities who are limited in their ability to perform daily activities independently. Participants were contacted by mail through the Children's Rehabilitation Centre (CRC). Participants provided demographic information and completed self-report questionnaires measuring maternal distress (i.e., Malaise Inventory, Mental Health Inventory) and perceptions of parent-professional interactions (i.e., Enabling Practices Scale). The Vineland Adaptive Behavior Scales, Classroom Edition was completed by teachers or primary therapists to assess child functional status. Restricted range in the obtained measures obscured the expected association between child functional status and both maternal distress and perceptions of parent-professional interactions. Trends in the results indicated that greater functional impairment was associated with greater stress in parent-child relationships and more stressful life circumstances ( $p < .05$ ); however, psychological symptoms of distress were less for mothers of severely impaired children, than for mothers of moderately impaired children. Implications for research and practice are discussed.

## DEDICATION

There were many people who contributed to the success of this project and who deserve acknowledgment; my committee members, Dr. Martin Girash, and Dr. Elizabeth Starr, thank-you for your enthusiasm and suggestions, and my supervisor, Dr. Sylvia Voelker, thank-you for your direction and encouragement. I also appreciated the time and energy demonstrated by the staff at the Children's Rehabilitation Centre, and all the mothers who participated in this project.

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## TABLE OF CONTENTS

<b>ABSTRACT</b>	<b>iv</b>
<b>DEDICATION</b>	<b>v</b>
<b>LIST OF TABLES</b>	<b>vii</b>
<b>CHAPTER</b>	
<b>I. INTRODUCTION</b>	
<b>Overview</b>	<b>8</b>
<b>Family-Centred Care</b>	<b>12</b>
<b>Rationale for the Shift to Family-Centred Care</b>	<b>14</b>
<b>Evidence of the Effectiveness of Family-Centred Care</b>	<b>18</b>
<b>Burden of Daily Care-Giving</b>	<b>19</b>
<b>Relationship Between Maternal Distress and Child Functional Status</b>	<b>22</b>
<b>Hypotheses</b>	<b>27</b>
<b>II. METHODOLOGY</b>	
<b>Participants</b>	<b>28</b>
<b>Measures</b>	<b>37</b>
<b>Procedure</b>	<b>42</b>
<b>Analyses</b>	<b>42</b>
<b>III. RESULTS</b>	
<b>Correlations of Demographic Variables with Predictor and Outcome Variables</b>	<b>44</b>
<b>Descriptive Statistics of Predictor and Outcome Variables</b>	<b>48</b>
<b>Hypothesis 1 - Supportive Parent-Professional Interactions</b>	<b>52</b>
<b>Hypothesis 2 - Child Functional Status</b>	<b>56</b>
<b>Hypothesis 3 - Predictors of Maternal Distress</b>	<b>58</b>
<b>IV. DISCUSSION</b>	<b>61</b>
<b>REFERENCES</b>	<b>68</b>
<b>APPENDICES</b>	
<b>Appendix A Family Information Questionnaire</b>	<b>76</b>
<b>Appendix B Enabling Practices Scale</b>	<b>78</b>
<b>VITA AUCTORIS</b>	<b>81</b>

## LIST OF TABLES

<b>Table 1</b>	<b>Demographic variables of participants with Vineland scores and participants without Vineland scores</b>	<b>31</b>
<b>Table 2</b>	<b>Descriptive statistics of demographic variables by level of adaptive ability</b>	<b>32</b>
<b>Table 3</b>	<b>Child disability characteristics</b>	<b>33</b>
<b>Table 4</b>	<b>Child and family demographic variables</b>	<b>35</b>
<b>Table 5</b>	<b>Descriptive statistics of service and support variables</b>	<b>36</b>
<b>Table 6</b>	<b>Demographic variables correlated with predictor and outcome variables (N=37)</b>	<b>45</b>
<b>Table 7</b>	<b>Demographic variables correlated with predictor and outcome variables (Low group, n=20)</b>	<b>46</b>
<b>Table 8</b>	<b>Demographic variables correlated with predictor and outcome variables (Moderate group, n=17)</b>	<b>47</b>
<b>Table 9</b>	<b>Descriptive statistics and normative data for predictor and outcome variables</b>	<b>49</b>
<b>Table 10</b>	<b>Descriptive statistics and normative data for predictor and outcome variables by group</b>	<b>51</b>
<b>Table 11</b>	<b>Correlations between Enabling Practices Scale and distress scores by group</b>	<b>53</b>
<b>Table 12</b>	<b>Descriptive statistics and normative data for Parenting Stress Index</b>	<b>54</b>
<b>Table 13</b>	<b>Descriptive statistics for Parenting Stress Index by group</b>	<b>55</b>
<b>Table 14</b>	<b>Correlations between Vineland ABC scores and distress scores by group</b>	<b>57</b>
<b>Table 15</b>	<b>Hierarchical regression analyses predicting maternal distress</b>	<b>59</b>

## CHAPTER I

### INTRODUCTION

#### Overview

The delivery of health care services to families of children with disabilities has shifted based on the growing recognition by health care practitioners that their attitudes and behaviours can influence parents' reactions to their children's disability (King, King, & Rosenbaum, 1996; Rosenbaum, King, & Cadman, 1992; Singer et al., 1993). The current trend is for programs to offer family-centred care (Dunst, Trivette, Davis, & Cornwell, 1988(a); Dyson & Fewell, 1986). The aim of family-centred programs is to enhance a family's adjustment to a child's disability by improving parent-professional interactions, and thereby reducing the amount of distress experienced by the family (Brewer, McPherson, Magrab, & Hutchins, 1989; Dunst, et al., 1988(a); Dunst, Trivette, & Deal, 1988(b); King et al., 1996; Nelkin, 1987; Shelton, Jeppson, & Johnson, 1987).

The development of family-centred programs was guided by medical and health care research, the focus of which was to reduce parental distress in parent-health care professional interactions (Rosenbaum et al., 1992). For health care services to be effective in allaying distress, families need to be actively involved in their child's care (Baine, Rosenbaum, & King, 1995; Cadman, Rosenbaum, Boyle, & Offord, 1991; Rosenbaum et al., 1992), and feel that they are in a supportive partnership with their child's health care providers (King et al., 1996; Kolobe, 1992; Minke & Scott, 1995).

The shift to a family-centred approach to health care service provision will have the greatest impact on families whose children require frequent contact with health care

professionals, such as children with developmental disabilities. The physical, emotional, and medical needs of children with developmental disabilities often require support and assistance from numerous health care professionals (e.g., medical personnel, occupational and physical therapists, support service staff such as social workers) (Crnic, Friedrich, & Greenberg, 1983; Rosenbaum et al., 1992). Health care professionals are often actively involved in both the short-term and long-term planning of educational and rehabilitation programs for children with disabilities (Lubetsky, Mueller, Madden, Walker, & Len, 1995).

Health care professionals have been identified by mothers as an important source of support (e.g., emotional and social support), as well as an important information resource (Lubetsky et al., 1995; Pelletier, Godin, Lepage, & Dussault, 1994). Maternal perceptions of support and the availability of information about the child's disability are related to maternal adjustment to the disability (Petersen, 1984; Singer et al., 1993). It follows then, that changing the nature of parent-professional interactions by improving communication, and encouraging a sense of partnership may improve maternal responses to a child's disability. However, enhancing the relationship between mothers and health care providers may not directly address distress associated with caring for a child with a developmental disability on a daily basis (Wikler, 1986).

Family-centred care practices involve all members of a family; however, they are mainly directed at the child's primary care-giver. While the challenges of meeting the medical, physical and emotional needs of a child with a disability affect the entire family (Crnic et al., 1983), the primary care-givers, which are usually the mothers (Jessop, Riessman, & Stein, 1988), often experience higher levels of distress than do other family members (Dunst et al., 1988(b)).

Therefore, the effects of the changes in health care service provision are expected to be most apparent in mothers' responses to their children's disability. The focus of the present study will be on the experiences of mothers of children with developmental disabilities whose physical and mental limitations affect their ability to perform daily activities independently.

The term 'developmental disability' encompasses a broad scope of disabling conditions that limit a child's physical and cognitive development. The term functional status is used to clarify a child's level of impairment by indicating a child's ability to perform daily activities independently (Dadds et al., 1995; Jessop et al., 1988; Sparrow, Balla, & Cicchetti, 1984; Stein & Jessop, 1990). A child's functional status is defined as the extent to which a disability affects the child's physical, social, emotional and cognitive development (Dadds, Stein, & Silver, 1995). A child who has a low level of functional ability will experience greater deficits in more developmental domains, than will a child who has a high level functional ability, who may only experience a mild degree of impairment in one or two developmental domains.

A child's level of functional ability determines the level of demands, and subsequent distress, experienced by the mother as the primary care-giver (Frey, Greenberg, & Fewell, 1989; Perrin, 1986). The relationship between maternal distress and the burden of caring for a child with low functional status is clearly established in studies of children with medical illnesses (Canning, Harris, & Kelleher, 1996; Jessop et al., 1988; Jessop & Stein, 1985; Lustig, Ireys, Sills, & Walsh, 1996; Silver, Bauman, & Ireys, 1995). However, due to methodological problems (e.g., small samples and limited measures of functional ability), there is only partial support in the literature for the relationship between maternal distress and the burden of care-giving for children with developmental disabilities (Breslau & Davis, 1985; Jessop et al., 1988;

Wallander et al., 1989). The first purpose of the present study is to address the methodological confounds of previous research on children with developmental disabilities, and to determine the relationship between care-giver burden and maternal distress.

The extent to which family-centred programs address the emotional needs of mothers of children with developmental disabilities has not been clearly established. It has been suggested that the beneficial effects of a family-centred program may be limited to allaying maternal distress that is related to specific aspects of a child's disability (e.g., the process of receiving a diagnosis, understanding the prognosis, or treatment planning) (Kovacs et al., 1985). The second purpose of the current study is to determine the degree to which supportive health care services address the distress experienced by mothers of children whose developmental disabilities require a high level of care.

The current emphasis in health care research is on improving parent-professional relationships, with the goal of reducing parental distress. While enhancing parent-professional interactions is a valuable goal, it is important to recognize that there are multiple factors associated with the distress experienced by mothers caring for children with developmental disabilities. A family-centred service program may be limited in the extent to which it can address the extensive emotional and physical demands faced by mothers of children with severely limited functional abilities. A more complete solution to improving the experiences of mothers of children with developmental disabilities may be to address the distress caused by the burden of daily care-giving. The third purpose of the current study is to assess maternal distress in relation to both supportive parent-professional interactions and to the burden of daily care-giving.

To provide a context for the current study, a description of family-centred care is presented, followed by a more detailed consideration of the rationale for the shift to family-centred models of service delivery for children with developmental disabilities. The effectiveness of programs that follow a family-centred model is outlined, and the limitations of such a model in improving maternal reactions to their child's disability are presented. Finally, research examining the psychological strain and physical burden of care-giving is reviewed.

### **Family-Centred Care**

There is growing evidence of a link between mothers' responses to their child's disability (i.e., their perceptions of their ability to manage the child's care, as well as the impact the disability may have on their family) and the attitudes and behaviours of professionals in health care services (Horn, Feldman, & Ploof, 1995; King et al., 1996; Rosenbaum et al., 1992; Singer et al., 1993). Mothers' perceptions of the quality of their interactions with service organizations (Perrin, 1986), as well as with individual practitioners (Knafl et al., 1992), are related to their responses to their child's disability. Both mothers and fathers of children with chronic physical disabilities (e.g., cerebral palsy) identified supportive parent-professional interactions as an important factor in "reducing stress and preventing worries" (Rosenbaum et al., 1992, p. 107).

As a result of these findings, changes are being made in the way services are provided to families of children with health problems. The focus of providing health care services is shifting from a child-centred approach to a family-centred approach (Dunst et al., 1988(a); Dyson & Fewell, 1986; Minke & Scott, 1995). There are two key changes in the shift to providing family-focused health care services. First, there is a change in the role of the health care practitioner. In a child-centred model, the focus of the practitioner is on evaluating and treating the child's

illness, whereas in a family-centred model, the focus of practitioners is on helping families manage their child's needs themselves (Dyson & Fewell, 1986). The second change in providing health care services is in the nature of parent-professional interactions. There is a shift away from the view of the practitioner as the expert, and a movement toward parents and professionals working collaboratively (Dunst et al., 1988(b)).

The goal of service providers that use a family-centred approach is to reduce the amount of distress, as well as enhance the confidence of those who are receiving care (Singer et al., 1993). By encouraging families to become active participants in the decision making and planning process for their child's treatment (Brewer et al., 1989; Nelkin, 1987; Shelton et al., 1987), as well as encouraging families to become knowledgeable about their child's disability (Dunst et al., 1988(a); Dunst et al., 1988(b)), family-centred programs attempt to address the distress experienced by mothers in managing their child's disability. Additionally, practitioners in family-centred programs expect that families will differ in the degree to which they want to be, or are able to be, involved in their child's care (Mittler & Mittler, 1983). As such, mothers who are involved in family-centred programs are able to choose the level of participation with which they are comfortable (Lubetsky et al., 1995). Through the recognition that mothers have different strengths and weaknesses (Dyson & Fewell, 1988), family-centred programs create treatment and education plans that are individualized to meet the needs of each family (Dunst et al., 1988(a); Dunst, Trivette, Gordon, & Starnes, 1993).

The trend toward family-centred programs is changing the attitudes and behaviours of health care practitioners in their interactions with families. The changes in health care services associated with family-centred programs will be equally important for both families of typically



developing children who require minimal health care services, and families of children with chronic medical conditions (such as diabetes) or developmental disabilities (such as mental retardation or cerebral palsy). However, the changes to providing health care services associated with family-centred care will have the greatest impact on families who are coping with the challenges associated with children with disabilities or chronic illnesses, and who require frequent support from health care professionals.

### **Rationale for the Shift Toward Family-Centred Health Care**

Caring for a child with multiple impairments has been found to contribute to the risk of mothers developing mental health problems (Rosenbaum et al., 1992). The shift in approach to providing health care services is based on evidence that health care practitioners have important and influential roles in the lives of mothers whose children require medical care.

Mothers of children with disabilities are often faced with the “unknown”; they are uncertain about the nature of their child’s disability and the potential impact of the disability on their families. Health care practitioners are able to provide mothers with information on the nature and prognosis of their child’s disability, as well as assessment results and regular updates on their child’s treatment (Lubetsky et al., 1995; Mittler & Mittler, 1983).

Social support is highly correlated with successful coping and positive adjustment to stressful events (Lubetsky et al., 1995). Health care practitioners provide emotional support and information, both of which are highly valued by mothers, and related to their adjustment to their child’s disability (Petersen, 1984; Singer et al., 1993). In addition to identifying family members and friends as essential elements of their support networks, parents of children with physical

disabilities also identify their child's health care professionals as an important source of support (Lubetsky et al., 1995; Pelletier et al., 1994).

Provision of health care services may be improved by examining how practitioners influence mothers' responses to their child's disability. Studies have examined the characteristics of individual health care providers and service programs to determine which aspects of services decrease distress and enhance mothers' confidence in their ability to manage the impact of their child's disability (King et al., 1996; Rosenbaum et al., 1992). A review of the medical and rehabilitation literature identifies three primary characteristics of professional behaviours and attitudes that are linked to mothers' positive responses to their child's disability: supportive and respectful parent-professional interactions, the sharing of information, and the inclusion of parents in making decisions about their child's care (Kenny, 1995; King et al., 1996; Friesen, Koren, & Koroloff, 1992; Rosenbaum et al., 1992; Schultz & Decker, 1985; Whitcher-Alagna, 1983). The following is a brief explanation of each key characteristic of parent-professional interactions that positively influence maternal responses to a child's disability. The following studies investigated the families of children with a mixture of disabling conditions, including physical disabilities (e.g., cerebral palsy), mental retardation, and children with multiple disabilities.

**Supportive and Respectful Interactions.** Interactions with health care providers that are perceived by mothers to be supportive and respectful are associated with decreased levels of distress and increased confidence (King et al., 1996). Respectful health care practitioners are identified by mothers as those whose attitudes toward both the parent and the child are warm, genuine and helpful (Baxter, 1989; Kenny, 1995). Practitioners whose behaviours toward the

child expressed genuine interest and concern were also considered to be respectful (Friesen et al., 1992; Kenny, 1995).

Mothers identify the continuity of their child's care as an important element in establishing a supportive relationship with their child's health care provider (Breslau, 1982; Breslau & Mortimer, 1981; Lubetsky et al., 1995). Having the same health care practitioner attend to their child's needs at repeat visits allows mothers to build a relationship with the practitioner (Rosenbaum et al., 1992). Practitioners who have built a relationship with mothers are in a better position to identify and address maternal distress (Breslau & Mortimer, 1981; Kenny, 1995).

**Shared information.** Mothers of children with disabilities are constantly facing the challenge of making decisions and choices regarding their child's care. A lack of adequate information to support these decisions contributes to mothers' stress (Horn et al., 1995; King et al., 1996; Kolobe, 1992). By providing mothers with information about their child's disability, health care providers help them to understand the disability, as well as to conceptualize the impact it will have on their families (McKenry & Price, 1994).

**Active involvement in planning and treatment.** Health care providers enhance mothers' sense of control over the care-giving process by encouraging mothers to actively participate in parent-professional interactions. Individuals who feel they have control over an event or situation are less likely to be debilitated by stress (Brickman et al., 1982; Reid, 1984). Mothers of children with a range of disabilities who felt that they had personal control over their child's care reported fewer symptoms of parenting stress (Affleck, Tennen, & Gershman, 1985; Frey et al., 1989; Silver et al., 1995). Mothers who felt that they were encouraged to be involved in

decision making about their child's health care reported experiencing lower levels of stress than did mothers who felt that they were not encouraged to participate (Cadman et al., 1991; King et al., 1996; Rosenbaum et al., 1992).

Taylor's cognitive coping theory identifies three coping strategies that are consistent with the three key elements of parent-professional interactions: the need to enhance self-esteem, the need to understand an event, and the need to perceive oneself as in control of an event (Taylor, 1983). By engaging parents in supportive and respectful interactions, practitioners can enhance mothers' self-esteem, thereby enhancing their beliefs that they are able to manage the challenges of caring for their child's disability. By providing accurate and up-to-date information, health care professionals can help mothers to understand and give meaning to their child's disability. By encouraging active participation and a sense of partnership, health care providers enhance mothers' sense of control over the health care process. These three cognitive coping strategies provide mothers with a way to re-frame their child's disability which may explain why supportive parent-professional interactions can be effective in reducing parents' distress. In sum, the three key elements of parent-professional interactions appear to be effective because they provide mothers with a way to adaptively evaluate and respond to a stressful situation (Taylor, 1983).

To summarize, there are three characteristics of health care services that are especially important for mothers of children with developmental disabilities: respectful and supportive interactions with health care providers, being informed about their child's care, and being involved in decision making and treatment planning. A possible explanation for the effectiveness of these three elements in reducing maternal distress may be that they provide mothers with adaptive coping strategies. It follows that health care services that incorporate these three

elements in service provision to families will positively influence maternal adjustment to having a child with a disability. A family-centred approach to providing health services includes these three key elements. However, the question remains whether family-centred programs have a positive effect on maternal well-being.

### Evidence of the Effectiveness of Family-Centred Care

There is some evidence that family-centred programs influence certain aspects of mothers' responses to their child's disability; two areas in particular are perceived control and perceived ability to cope. Interactions with health care professionals that follow a family-centred model enhance mothers' perceptions of their ability to manage their child's needs, which in turn decreases the amount of distress they experience (Dunst & Paget, 1991; Minke & Scott, 1995).

Several studies have compared responses of mothers who participated in different models of service programs for their children's health care. Mothers who participated in family-centred programs reported experiencing higher levels of perceived control than did mothers in child-centred programs (Dunst et al., 1988(a); Trivette, Dunst, Boyd, & Hamby, 1996(a); Trivette, Dunst & Hamby, 1996(b)). Parents who reported feelings of being in control in parent-professional interactions reported lower levels of distress than did parents who felt they did not have control (Marcenko, Herman, & Hazel, 1992). In sum, these studies provide evidence that positive parent-professional interactions influence maternal adjustment to a child's disability. However, it is not clear that the adaptive coping strategies learned through supportive parent-professional interactions will address other causes of distress related to the child's disability, such as the burden of daily care-giving.

It is possible that the beneficial effects of family-centred programs may be limited to addressing maternal distress that is specific to a child's diagnosis, prognosis, or treatment. If this is the case, then a shift toward family-centred service programs will be helpful only at specific times in the child's life, and will not address the distress caused by the burden of managing daily care-giving demands.

Mothers of children with developmental disabilities experience an increase in distress at transition points in their child's life (e.g., following the diagnosis, special school placement, puberty) (Thompson et al., 1994; Wikler, 1986). A supportive relationship with health care professionals may be especially important during these transition stages, when mothers require extra information about their child's disability, or need to reassess their child's treatment plans. At these times the quality of parent-professional interactions will have a strong role in mediating maternal adjustment, because mothers' stress will be related specifically to knowledge about their child's disability. However, the role of supportive parent-professional interactions in reducing distress during the "in-between" times, when mothers are coping with the daily strain of care giving, is not clearly understood.

### Burden of Daily Care-Giving

Caring for a child with multiple limited functional abilities on a daily basis is both physically and emotionally demanding. Quine and Pahl (1985) reported that for mothers of children with multiple impairments, the degree of care giving demands was strongly related to physical and psychological symptoms of distress. The following is a brief outline of the emotional and practical issues that face mothers of children with functional impairments on a daily basis.

**Emotional demands of caring for child with physical disabilities.** Following the initial shock of receiving the diagnosis of a child's disability, mothers face feelings of grief, guilt and frustration as they come to terms with the implications of their child's disability (Santelli, Turnbull, Lerner, & Marquis, 1993). The impact of the disability on the family (Jessop et al., 1988) and the child's prognosis (McCubbin, 1989) are often uncertain, and an on-going source of worry. Mothers often report feeling unsure of their ability to cope with their child's needs (Dyson & Fewell, 1986; McCubbin, 1989). Attending to the needs of a child with a disability often disrupts family routines and as a result, mothers have less time available for other family members (Breslau & Parbucki, 1987). Additionally, the lack of accessibility of many public venues, as well as the stigma often associated with a disability may result in the family feeling isolated from the community (Jessop et al., 1988). Together these issues add emotional strain to the already challenging task of raising a child with a disability.

**Practical demands of caring for a child with physical disabilities.** The practical demands of caring for a child with limited functional abilities requires a great deal of time and energy on the part of the child's primary care-giver (Dyson & Fewell, 1986; Jessop et al., 1988). The primary care-giver often needs to schedule and attend frequent appointments with specialists for educational, medical and rehabilitative support (Jessop et al., 1988; McCubbin, 1989). In addition, mothers often take on the role of health care professional in the home. This role includes learning and performing nursing and physical therapy tasks, such as attending to the child's complicated medical needs or daily exercise routines, both of which may involve learning to operate specialized equipment (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989; Jessop et al., 1988; McCubbin, 1989; Wallander & Venters, 1995). Mothers of children with

limited communication skills often must learn alternative forms of communication and teach them to the child, the family members, and the child's educators (Santelli et al., 1993). The learning and teaching process places an additional demand the care-giver's time.

It is often difficult to find appropriate respite care for children with disabilities, especially for children with complex medical needs and a high degree of dependence on a care giver (Warfield & Hauser-Cram, 1996). Due to limited respite care, mothers often have to take time away from work, or work fewer hours outside the home in order to manage the needs of the child (Breslau, Salkever, & Staruch, 1982; Wallander & Venters, 1995). The decreased time available for work, as well as the need for specialized equipment and professional help can result in financial strain (Dyson & Fewell, 1986).

One of the greatest challenges faced by mothers of children with disabilities is finding time for themselves (Gowen et al., 1989). The lack of appropriate respite care limits mothers' opportunities for social outings and the amount of time and energy they have available to pursue personal interests (Biegel, Sales, & Shultz, 1991; Wallander & Venters, 1995). Mothers who are unable to take time away from their child often experience higher levels of stress than do mothers who have adequate respite care (Chetwynd, 1985; Gowen et al., 1989).

The degree to which a child's disability limits the child's physical, cognitive, social and self-help skills determines the degree of care-giving demands placed on the mother. A child with a low level of functional ability will present more practical constraints and emotional demands for a care-giver, than will a child who is able to function more independently (Gowen et al., 1989).



### **Relationship Between Maternal Distress and Child Functional Status**

There is compelling evidence in the stress and coping literature that mothers of children with developmental disabilities experience high levels of distress, and their responses cover a range of psychological and physical symptoms of distress. (Baine, Rosenbaum, & King, 1995; Breslau, Staruch, & Mortimer, 1982; Cadman et al., 1991; Cadman, Boyle, Szatmari, & Offord, 1987). However, due to methodological limitations (e.g., small sample size, limited measures of functional ability) most studies involving children with developmental disabilities have not clearly established that child functional status is associated with maternal distress.

**Medical conditions and functional status.** Studies of illness-related functional limitations provide support for the relationship between functional status and maternal well-being (Canning et al., 1996; Jessop et al., 1988; Jessop & Stein, 1985; Lustig et al., 1996; Silver et al., 1995). The degree to which an illness limits a child's ability to participate in daily activities, or increases the child's dependence on the mother for medical care (e.g., insulin injections for children with diabetes) is strongly connected to maternal distress (Jessop et al., 1988; Silver et al., 1995). Additionally, mothers whose children required complicated health care procedures (e.g., tube feedings) reported higher levels of psychological distress and depression (Beckman, 1983; Breslau & Davis, 1986; Gowen et al., 1989), than did mothers of children with less medically involved illnesses (Jessop et al., 1988).

**Limitations of evidence in the medical literature.** The findings from the medical literature (e.g., studies on mothers of children with diabetes or cystic fibrosis) cannot be extended directly to the experiences of mothers of children with developmental disabilities due to the differences in the children's level of needs. Children with developmental disabilities often have

physical and cognitive limitations, as well as medical conditions which severely limit their ability to perform daily tasks without the assistance of a care-giver. In contrast, only a small proportion of children with medical conditions are limited in their daily activities (Silver et al., 1995), and they are less likely than children with developmental disabilities to require adult assistance in daily tasks (Jessop et al., 1988).

An additional difference between children with developmental disabilities and children with chronic medical conditions is in the treatment of the symptoms of their illness or disability. In general, the limitations experienced by children with developmental disabilities can be minimized, but not eliminated. For example, physical limitations such as poor muscle control can be improved through physical therapy, and limited mobility can be improved through the use of specialized equipment such as splints or wheelchairs. However, children with physical or cognitive limitations usually remain impaired to some degree, and as a result require the ongoing assistance of a care-giver. In comparison, the symptoms of many chronic illnesses can be effectively treated through medication (e.g., diabetes). Subsequently, the mothers of the two groups of children will experience different levels of care-giving demands.

The evidence of a relationship between maternal distress and child functional status in the medical literature suggests the potential for a similar relationship for mothers of children with developmental disabilities. However, given the differences in care-giving experiences, generalizations between the two groups should be made cautiously.

Physical disabilities and functional status. Studies which investigated the psychological and physical symptoms of stress experienced by mothers of children with developmental disabilities yielded conflicting results (Fagan & Schor, 1993; Wallander, Pitt, & Mellins, 1990; Wallander &

Venters, 1995). Some studies reported that mothers of children with developmental disabilities experienced higher levels of distress than did mothers of typically developing children (e.g., Breslau & Davis, 1985) while other studies found that the levels of distress in mothers of children with disabilities were not different from the levels of distress experienced by mothers of children without disabilities (e.g., Kazak & Marvin, 1984).

Canning et al. (1996) hypothesized that the omission of child functional status as a predictor of distress may contribute to the disparities in previous research. Studies that included severely disabling conditions generally reported higher levels of distress among care givers (e.g., Breslau, Staruch, & Mortimer, 1986), whereas studies that included less disabling conditions, such as mild cerebral palsy, have found little or no increase in symptoms of maternal distress (e.g., Kovacs et al., 1985). This discrepancy suggests that a child's functional status is an important variable to consider when evaluating factors that mediate maternal levels of distress.

A review of the childhood disability literature indicated that a number of variables, in addition to a child's functional status, may contribute to maternal distress and as a result, contribute to the disparity in the previous research. For example, the age at which the child was diagnosed, and the length of time the family has had to adjust to the disability, may contribute to the degree of distress reported by mothers (Dadds et al., 1995; Jessop et al., 1988; Wallander et al., 1989). Variables that are associated with maternal perceptions of burden (e.g., the amount of support available to the family, the accessibility of respite care, and the socio-economic status of the family) may also influence levels of reported maternal distress (Canning et al., 1995; Fagan & Schor, 1993; Weiss, 1991). Therefore, in addition to child functional status, it is necessary to

assess child, family, and maternal support variables, when examining variables associated with maternal distress.

There are few studies in the childhood disability literature that assess the influence of functional status when investigating factors that influence maternal well-being (Breslau & Davis, 1986; Wallander et al., 1990). The studies that have assessed the relationship between functional status of children with physical disabilities and maternal distress have methodological limitations, such as small sample sizes, or limited measures of functional impairment.

In an investigation of the role of social support in mediating distress in mothers of children with disabilities ( $n=15$ ) Dyson and Fewell (1986) found a small, but significant, relationship between the degree of a child's impairment and the level of psychological symptoms of distress experienced by mothers. However, the children's disabilities affected different aspects of functional ability (e.g., physical disability, sensory impairment, mental retardation). The small sample size and the diverse nature of the children's functional limitations made interpretation of the results difficult.

Breslau, Staruch and Mortimer (1982) investigated the relationship between childhood disabilities and the level of psychological distress experienced by mothers. They found a significant positive relationship between the child's dependence on the mother in daily activities and maternal distress. Their sample consisted of 369 children with similar levels of physical impairment, including children with cystic fibrosis, cerebral palsy and multiple physical handicaps. However, the measure used to assess the children's functional limitations addressed relatively few of the developmental domains that may be affected by a physical disability (e.g.,

the measure did not assess communication skills), and as a result the relationship between a child's disability and maternal well-being may have been underestimated.

In sum, there is strong support in the medical literature, and partial support in the disability literature for the relationship between a child's functional limitations and the level of distress experienced by mothers. The disability literature is limited by methodological weaknesses, therefore further research needs to be conducted to clarify the relation between child functional status and maternal distress.

### **Present Study**

The goal of the present study was to assess the relative impact of family-centred health care and child functional status on maternal stress. There is empirical evidence that family-centred programs address maternal distress that is specific to a child's diagnosis, prognosis and treatment (Dunst et al., 1988(a); Dunst & Paget, 1991; Minke & Scott, 1995; Trivette et al., 1996(a); Trivette et al., 1996(b); however, it is not clear that a shift toward family-centred service programs will address maternal distress that is related to the burden of daily care giving. There is compelling evidence in the medical literature that the functional status of chronically ill children, and the subsequent amount of burden experienced by mothers, is related to maternal stress (Beckman, 1983; Breslau & Davis, 1986; Canning et al., 1996; Gowen et al., 1989; Jessop et al., 1988; Jessop & Stein, 1985; Lustig et al., 1996; Silver et al., 1995;). However, there are few studies that assess the influence of the functional status of children with developmental disabilities on maternal well-being (Breslau & Davis, 1986; Wallander et al., 1990), and these studies are difficult to interpret due to methodological limitations.

The present study will assess the influence of family-centred health care services on maternal distress. As well, the present study will assess the influence of functional status of children with developmental disabilities on maternal distress. Finally, the present study will examine the relative impact of both family-centred health care services and child functional status on maternal distress.

#### **Hypothesis 1 - Supportive Parent-Professional Interactions.**

(a) It was hypothesized that maternal perceptions of supportive parent-professional interactions would be associated with lower levels of maternal distress.

(b) It was further hypothesized that the relationship between maternal perceptions of support and maternal distress would vary with the perceived source of distress. Distress that was associated with child characteristics, as opposed to distress associated with parent characteristics or life events would be more strongly related to the level of perceived support from professionals.

#### **Hypothesis 2 - Child Functional Status.**

It was hypothesized that low child functional status and the subsequent burden experienced by mothers would be associated with increased maternal distress compared to the distress experienced by mothers of children with high functional status.

#### **Hypothesis 3 - Predictors of Maternal Distress.**

It was predicted that overall maternal distress would be more strongly related to child functional status than to the level of support perceived by mothers in their interactions with health care professionals.

## CHAPTER II

### METHOD

#### Participants

The present research project was conducted at the Children's Rehabilitation Centre of Essex County (CRC). CRC offers family-centred services to children whose disabilities limit their functional ability (e.g., motor, communication, self-help, and socialization skills). The staff at CRC follow guidelines that encourage the active participation of parents in treatment and planning decisions. Each family that receives services from CRC is assigned a case manager who is responsible for ensuring that the family receives accurate information about the supports and services that are available.

The disabilities of the majority of the children at CRC usually result in limitations to multiple aspects of the child's functional ability (e.g., cerebral palsy or multiple physical handicaps combined with mental retardation). In addition to the specialized education and rehabilitative programs provided by the preschool and day-school programs, CRC also offers rehabilitative services on an out-patient basis including physiotherapy, occupational therapy, and speech and language therapy. Family Services (i.e., social worker, in-home support) and bi-annual medical clinics are also available.

Participants were 37 mothers or female primary care-givers of children who attended one of the two CRC school programs ( $n=17$ ), or received out-patient services ( $n=20$ ). From this point the two CRC school programs (i.e., preschool program and day-school program) will be referred to as the CRC program. Initially the administrative staff at CRC identified a pool of 300 potential participants whose children had been involved in either the CRC school program or out-

patient service program for at least 6 months. Of the 300 potential participants, 65 (22%) indicated an interest in participating and were sent questionnaires. Fifty-three (81.5%) of the 65 participants returned the questionnaires. Fifteen questionnaires were discarded because the child's age was not within the designated range (9 children <3 years and 6 children >12 years-11 months). One questionnaire was excluded because the nature of the child's disability did not require on-going services from CRC (i.e, consultation for a speech impairment), resulting in a sample size of  $N=37$ (12% of the population).

Vineland forms were not completed by teachers or therapists for 8 (22%) of the 37 participants' children, so estimation of the functioning level of these children was based on other available information (i.e., child variables, service and support variables). This subset of participants did not seem to differ from the remainder of the sample in any meaningful way (Table 1).

The 8 children without Vineland forms were diagnosed later than the majority of the sample, which may suggest that the disabilities of the 8 children were not as obvious as those of the rest of the children in the sample, and possibly not as severe. The two groups did not differ in the nature of the services they received from CRC. Of the support variables, the 8 participants without Vinelands received more support from outside services (e.g., respite care) than did the other children, possibly because it is easier to find respite for less severely impaired children. Overall, the 8 children do not appear to be substantially different from the remainder of the sample, which provides some justification for using the mean Vineland Adaptive Behavior Composite (ABC) score (70.8) of the children with Vineland forms, as an estimate of the functioning level of the children without Vineland forms.



A summary of demographic variables was calculated for each of the five levels of functional ability, as determined by the Vineland ABC scores (Table 2). The majority of the children in this sample ( $n=20$ , 54.1%) scored in the Low Adaptive Ability range (standard score of 0-69). Of the 17 other children, 12 (32.4%) scored in the Moderate-Low Adaptive Ability range (standard score of 70-84); four (10.8%) scored in the Adequate Adaptive Ability range (standard score of 85-115); and one (2.7%) was categorized in the High Adaptive Ability range (standard score of 131-160). There were no children in the Moderate High Adaptive Ability category (standard score of 116-130).

The Vineland ABC scores were used to divide the participants into two sub-groups. Mothers of children with severely impaired functional ability (i.e., scored in the low range of the Vineland ABC, 0-69) formed the Low Functional Status group (Low), and mothers of children with moderate to mild impairments in their functional ability (i.e., scored between moderate-low and high range of the Vineland ABC, 70-160) formed the Moderate Functional Status group (Moderate).

### Child and Family Characteristics.

A summary of the children's disabilities is presented in Table 3 for the total sample, as well as for the two sub-groups (i.e., Low and Moderate). Children with more than one diagnosis (e.g., cerebral palsy and a sensory impairment) were grouped under the heading "Multiple Disabilities." Children with congenital disabilities, other than cerebral palsy and spina bifida (e.g., Juvenile Rheumatoid Arthritis, Duchenne's Muscular Dystrophy), were categorized as "Other Congenital Disabilities." The two children whose disabilities were not congenital (e.g., acquired traumatic brain injury) were labeled "Non-congenital Injury."

**Table 1**  
**Demographic Variables of Participants with Vineland Scores (n=29) and Participants Without Vineland Scores (n=8)**

	Participants with Vineland scores (n=29)		Participants missing Vineland scores (n=8)		t
	M	SD	M	SD	
<b>Child Variables</b>					
Age (in months)	76.8	41.9	58.0	24.7	n.s.
Age at diagnosis (in months)	8.3	9.2	21.0	21.2	-2.43*
<b>CRC Status <sup>a</sup>:</b>					
School	15	(51.7)	2	(25.0)	
Out-Patient	14	(48.3)	6	(75.0)	
<b>Service/Support Variables</b>					
Length of time at CRC (months)	54.3	42.6	32.6	21.9	n.s.
Number of services received from CRC	3.3	1.2	2.9	1.4	n.s.
Meetings with CRC staff (per year)	18.6	23.6	39.0	23.8	n.s.
Number of services received from other resources	0.7	0.9	2.1	1.4	-3.56**
Support from other resources (hrs per week)	14.8	36.2	32.0	28.3	n.s.

<sup>a</sup> Values indicate frequencies and (percentages)

\*  $p < .05$

\*\*  $p < .01$

**Table 2**  
**Descriptive Statistics of Demographic Variables by Level of Adaptive Ability**

	Vineland Level of Adaptive Ability			
	Low (0-69) (n=20)	Moderate-Low (70-84) (n=12)	Adequate (85-115) (n=4)	High (131-160) (n=1)
<b>Child Variables (M, SD)</b>				
Age (in months)	73.5 (44.1)	62.3 (26.1)	96.5 (49.5)	89.0
Age at Diagnosis (in months) <sup>a</sup>	8.1 (8.0)	17.0 (19.6)	6.5 (5.5)	36.0
Sex <sup>b</sup> :				
Male	14 (70.0)	6 (50.0)	1 (25.0)	
Female	6 (30.0)	6 (50.0)	3 (75.0)	1 (100.0)
CRC Status <sup>b</sup> :				
School	13 (65.0)	4 (33.3)		
Out-Patient	7 (35.0)	8 (66.7)	4 (100.0)	1 (100.0)
Disability <sup>a</sup>				
Multiple Disabilities	8 (40.0)	2 (16.7)	1 (25.0)	
Cerebral Palsy	3 (15.0)	4 (33.0)	3 (75.0)	
Other Congenital Disabilities	3 (15.0)	2 (16.7)		1 (100.0)
Global Developmental Delay	2 (10.0)	3 (25.0)		
Spina Bifida	1 (5.0)	1 (8.3)		
Non-congenital Injury	2 (10.0)			
<b>Service and Support Variables (M, SD)</b>				
Length of time at CRC (months)	51.8 (43.8)	39.8 (26.3)	66.0 (54.8)	-
Number of services received from CRC	3.6 (1.1)	2.8 (1.2)	2.8 (1.3)	1.0 (0.0)
Meetings with CRC staff (per year)	20.1 (25.4)	27.9 (23.8)	27.5 (34.7)	4.0 (0.0)
Number of services received from other resources	0.9 (0.8)	1.6 (1.5)	0.7 (1.2)	-
Support from other resources (hrs per week)	21.1 (42.1)	12.8 (22.5)	-	-
Accessibility of respite care <sup>c</sup>	2.7 (2.0)	3.1 (1.1)	1.3 (1.2)	-
Availability of respite care <sup>d</sup>	1.5 (1.4)	2.3 (0.9)	1.0 (1.0)	-

<sup>a</sup> Excludes children with Non-congenital Injuries, n=2

<sup>b</sup> Values indicate Frequency and (Percentage)

<sup>c</sup> Scale of 0-5, lower scores indicate greater accessibility

<sup>d</sup> Scale of 0-4, lower scores indicate greater availability

**Table 3**  
**Child Disability Characteristics**

	<b>Total N (N=37)</b>		<b>Low (n=20)</b>		<b>Moderate (n=17)</b>	
<b>Diagnosis</b>	<b>Frequency (%)</b>		<b>Frequency (%)</b>		<b>Frequency (%)</b>	
<b>Multiple Disabilities</b>	11	(29.7)	8	(40.0)	3	(17.6)
<b>Cerebral Palsy</b>	10	(27.0)	3	(15.0)	7	(41.2)
<b>Other Congenital Disorders</b>	7	(18.9)	4	(20.0)	3	(17.6)
<b>Global Developmental Delay</b>	5	(13.5)	2	(10.0)	3	(17.6)
<b>Non-congenital Injury</b>	2	(5.4)	2	(10.0)		
<b>Spina Bifida</b>	2	(5.4)	1	(5.0)	1	(5.9)

Child and family demographic variables are summarized in Table 4. The age range of the children at the time of the research project was 3 years to 12 years-11 months, with an average age of 6.02 ( $SD=3.31$ ) years. Excluding the two children with non-congenital injuries, the average age at which a diagnosis was given was 11.3 months ( $SD=13.7$  months). The two children with non-congenital injuries were injured at the ages of four months and 23 months. At the time of the study these two children were three years and 10.9 years of age, respectively. Approximately one-third (35.2%) of the children in this sample had been diagnosed at birth, and the majority (76.4%) had received a diagnosis by the end of their first year.

The majority of children in this sample were from intact 2-parent families ( $n=30$ ). In the 7 single-parent families the mother had custody of the child. The number of children in each family ranged from 1-7, with a mean of 2.7 ( $SD=1.3$ ) children. The average level of socio-economic status of the participants was 3 on a scale of 1-5, equivalent to that of a skilled labourer or clerical worker (Hollingshead, 1975). *T*-tests indicated that there were no significant differences ( $p>.05$ ) between the Low and Moderate groups on the child and family demographic variables.

### **Service and Support Characteristics**

The characteristics of the services received by the participants from CRC, as well as from other resources outside of CRC, are summarized in Table 5. On average, participants and their children had been involved in programs at CRC for four years ( $M=4$  years-1 month,  $SD=3$  years-3 months). In general, children with more severely limited functional abilities had been involved with CRC for a longer period of time than had children with less severe functional impairments.

**Table 4**  
**Child and Family Demographic Variables**

	Total N (N=37)	Low (n=20)	Moderate (n=17)
<b>Child Variables</b>			
Age (in months) <sup>a</sup>	72.8 (39.3)	73.5 (44.1)	71.9 (34.1)
Age at diagnosis (in months) <sup>b</sup>	11.3 (13.7)	6.5 (6.5)	16.1 (17.3)
Sex <sup>c</sup> :			
Male	21 (56.8)	14 (70.0)	7 (41.2)
Female	16 (43.2)	6 (30.0)	10 (58.8)
CRC Status <sup>c</sup> :			
School Program	17 (45.9)	13 (65.0)	4 (23.5)
Out-Patient	20 (54.1)	7 (35.0)	13 (76.5)
<b>Family Variables</b>			
SES <sup>a</sup>	3.1 (1.3)	3.0 (1.1)	3.2 (1.5)
Family Status <sup>c</sup> :			
1-parent	7 (18.9)	4 (20.0)	3 (17.6)
2-parent	30 (81.1)	16 (80.0)	14 (82.4)
Number of Children <sup>a</sup>	2.7 (1.3)	2.6 (1.2)	2.8 (1.2)

<sup>a</sup> Values indicate Means and (Standard Deviations)

<sup>b</sup> Excludes children with Non-congenital Injuries, n=2

<sup>c</sup> Values indicate Frequency and (Percentage)

**Table 5**  
**Descriptive Statistics of Service and Support Variables**

	Total N (N=37)		Low (n=20)		Moderate (n=17)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Length of time at CRC (months)	49.2	39.5	51.8	43.8	46.3	35.3
Number of services received from CRC	3.2	1.2	3.6	1.1	2.7	1.2
Meetings with CRC staff (per year)	22.3	24.5	20.1	25.4	25.6	23.8
Number of services received from other resources	1.0	1.2	0.9	0.9	1.3	1.4
Support from other resources (hrs per week)	16.3	35.3	21.1	42.1	8.0	18.3
Accessibility of respite care <sup>a</sup>	2.6	1.8	2.7	2.0	2.5	1.5
Availability of respite care <sup>b</sup>	1.7	1.3	1.5	1.4	1.9	1.2

<sup>a</sup> Scale of 0-5, lower scores indicate greater accessibility

<sup>b</sup> Scale of 0-4, lower scores indicate greater availability

Most children received more than three ( $M=3.2$ ,  $SD=1.2$ ) services from CRC; including services from the school program, Family Services, and the rehabilitation programs. Children with more severe functional limitations received significantly more services than did children with mild functional limitations ( $t(35) 2.41$ ,  $p<.05$ ). There was a broad range in the number of meetings between participants and CRC staff (range 2-73 meetings per year,  $M=22.3$ ,  $SD=24.5$ ). The majority of the children and their families received services from one other ( $M=1.0$ ,  $SD=1.2$ ) support program (e.g., Infant and Family Program, Respite Services) in addition to the services received from CRC. While children in the Moderate group received slightly more services outside of CRC than did children in the Low group, children in the Low group received more hours of services per week from other resources.

### Measures

Family Information Questionnaire. The Family Information Questionnaire was designed by the researcher to summarize 16 demographic variables including the nature of the child's disability; general information regarding the participant's family; and the types of services the family received from the Children's Rehabilitation Centre and other resources (Appendix A). The occupation and level of education of both parents were used to calculate the socio-economic status of each family based on Hollingshead's Four Factor Index of Social Status (Hollingshead, 1975).

Enabling Practices Scale (Dempsey, 1995). The Enabling Practices Scale (EPS), used with permission from the author, is a 24-item self-administered questionnaire designed to assess parents' perceptions of the services provided by programs for children with disabilities (Appendix B). The EPS is a relatively new scale, and one of the few measures that evaluates the



effectiveness of service programs from the perspective of parents of children with disabilities. The EPS was originally developed to evaluate the effectiveness of supervised work settings by parents of adult children with disabilities (Dempsey, 1995). The EPS is equally applicable to programs which provide services to young children with disabilities.

Items on the EPS are divided into three sub-scales which identify three key aspects of parent-professional interactions: the degree of comfort parents experience in parent-staff relationships, the extent to which parents feel there is a sense of collaboration with the staff members, and the level of perceived parental autonomy. The Comfort sub-scale indicates the quality of communication and interactions between parents and staff (e.g., "The staff's suggestions for working with my son/daughter make me feel comfortable.") The Collaboration sub-scale assesses the extent to which parents feel they are in a partnership with the staff (e.g., "The staff and I agree on what is most important in my son's/daughter's program.") The Parental Autonomy sub-scale measures parents' perceived control over decisions relating to their child's care (e.g., "I am the person who makes the most important decisions about my son's/daughter's program.")

Items on the EPS are rated on 5-point Likert scales ranging from Very Untrue (1) to Very True (5). The final scores on each of the sub-scales are summed to yield an Empowerment score, which represents the parents' overall perception of the services provided by the program. The internal consistency coefficients for the sub-scales of Comfort, Collaboration and Parental Autonomy were 0.95, 0.85 and 0.70 respectively. Factor analysis of the EPS suggested that it is a valid measure of service practices (Dempsey, 1995). The EPS is particularly valuable for the

present study as it provides an indication of mothers' perceptions of the health care services their child receives at CRC

**Parenting Stress Index** (Abidin, 1995). The Parenting Stress Index (PSI) is a 120 item self-report questionnaire that measures the levels of three different domains of stress in a parent-child relationship: child characteristics, parent characteristics and situational/ life stress. A comparison of the three domain scores indicates the primary source of stress in a parent-child relationship. For example, a higher score on the Child characteristics domain, than on either the Parent characteristics domain or Life Stress domain indicates that child characteristics are the main contributing factor to overall stress in a parent-child relationship.

The Child and Parent Domain scores are derived from the sum of six separate sub-scales. The Child Domain score is based on the parent's perception of the child's Destructibility/Hyperactivity, Adaptability, Reinforcement of Parent, Demandingness, Mood and Acceptability. The Parent Domain score is the sum of six sub-scale scores: Competence, Isolation, Attachment, Health, Role Restriction, Depression and Spouse. Both the Child and Parent Domain items are rated on 5-point Likert scales ranging from one (strongly disagree) to five (strongly agree). The Total Stress score is the sum of both the Child Domain score and the Parent Domain score. The Life Stress Domain score is the sum of scores for 19 possible stressful events. Raw scores are converted to percentiles, and scores at or above the 85<sup>th</sup> percentile indicate a high level of stress for all scales and sub-scales.

The internal consistency (Cronbach alpha) ranged from 0.70 - 0.83 on the Child domain, and 0.70-0.84 on the Parent domain indicating a high degree of internal consistency. The test-retest coefficients the Child Domain, Parent domain, and Total Stress score were 0.63, 0.91, and

0.96 respectively (Abidin, 1995). The PSI has been used extensively in research of families of children who have disabilities, or children who require pediatric services, and has demonstrated adequate construct validity (Abidin, 1995; Goldberg et al., 1990).

Vineland Adaptive Behavior Scales - Classroom Edition (Harrison, 1985). The Vineland Adaptive Behavior Scales were developed to assess the level of adaptive behavior exhibited by children with disabilities (Sparrow, Balla, & Cicchetti, 1984). The Vineland measures a child's performance in four domains of adaptive behavior: Communication, Daily Living Skills, Socialization, and Motor Skills. The Classroom Edition of the Vineland is a 244 item questionnaire administered to teachers that takes approximately 20 minutes to complete.

Standard scores are calculated for each of the four domains. The standard scores are summed to determine the Adaptive Behavior Composite score (ABC). The ABC score is used to determine the child's level of adaptive ability on a five level scale; Low Adaptive Ability (69 and below), Moderately Low Adaptive Ability (70-84), Adequate Adaptive Ability (85-115), Moderately High Adaptive Ability (116-130), and High Adaptive Ability (131 and above).

The Vineland manual indicates strong internal consistency for the four domains and the ABC (Communication 0.88-0.95, Daily Living Skills 0.92-0.96, Socialization 0.91-0.96, Motor Skills 0.77-0.84, and ABC 0.96-0.98) (Harrison, 1985). The Vineland also demonstrates adequate construct and content validity (Harrison, 1985). Additional information on the reliability and validity of the Classroom Edition of the Vineland is available in the administration manual (Harrison, 1985).

Maternal Well-Being Two instruments that assess different aspects of distress were used. The first, the Mental Health Inventory (Davies, Sherbourne, Peterson, & Ware, 1988) measures

symptoms of emotional distress, and the second, the Malaise Inventory (Rutter et al., 1970), measures physical symptoms of distress.

The Mental Health Inventory (MHI) is a 43-item self-report scale that assesses the participant's experience of the most common symptoms of psychological distress. Participants use either a 6- or a 5- point rating scale to indicate the frequency or intensity of a behavior or emotion that they had experienced over the past 6 months. Depending on the sub-scale, high overall scores indicate either high levels of distress, or high levels of well-being. Higher Mental Health Index scores indicate more well-being. The items on the MHI can be scored to yield 6 sub-scales: Anxiety (e.g., I feel anxious and worried), Depression (e.g., I have felt downhearted and blue), Loss of Behavioral/Emotional Control (e.g., I am concerned about losing control of my mind), General Positive Affect (e.g., I am a happy person), Emotional Ties (e.g., I have felt loved and wanted), and Life Satisfaction (e.g., I have been happy with my personal life); two global scales (Psychological Well-Being and Psychological Distress), and an overall indicator of mental health (Mental Health Index).

The MHI demonstrated adequate concurrent and construct validity as a measure of level of distress (Davies et al., 1988). The internal consistency of the 6 sub-scale scores ranged from 0.81 (Emotional Ties) to 0.94 (Psychological Distress) (Veit & Ware, 1983). The internal consistency of the Mental Health Index score is 0.96 (Davies et al., 1988). The MHI is frequently used in the general population, and is appropriate for use with mothers of children with disabilities (Wallander & Noojin, 1995).

The Malaise Inventory (MI) is a 24-item self-report checklist of psychosomatic symptoms that are commonly associated with distress (e.g., I am easily upset or irritated). The participants

indicate whether each of the statements had applied to themselves over the past month by endorsing either Yes or No. Reports of 5 or more positive endorsements indicate that the respondent is experiencing a high level of psychological distress (Grant, Nolan, & Ellis, 1990; McGee, Williams, & Silva, 1986). The MI has demonstrated good construct validity (McGee, Williams, & Silva, 1986; Rutter et al., 1970) and satisfactory internal reliability (McGee, Williams, & Silva, 1986). The MI is frequently used to measure the levels of distress reported by mothers of children with severe physical disabilities (Grant, Nolan, & Ellis, 1990; Rutter et al., 1970; Sloper, 1996).

### Procedure

Participants were initially contacted by mail through CRC, and invited to participate in the study. The 65 mothers or female primary care-providers who indicated an interest in participating were sent a questionnaire package which included the Family Information Questionnaire, Enabling Practices Scale, Mental Health Inventory, Malaise Inventory, Parenting Stress Index, and a return envelope. Diagnostic information and Vineland scores for each child were collected from CRC files. The Vineland Adaptive Behavior Scale-Classroom Edition was completed by the classroom teacher or primary therapist of the children who did not have a Vineland form on file. Participants who returned the questionnaire packages were sent a scratch-and-win lottery ticket along with a debriefing letter, and were also entered in a draw for a dinner.

### Analyses

The degree of association between the two outcome measures of maternal distress (i.e., Malaise Inventory and Mental Health Inventory) was assessed with Pearson Product Moment correlations. Results indicated a moderate degree of association between the Mental Health

Index score and the Malaise Inventory total score for the total sample ( $r = -0.62, p < .01$ ), the Low group ( $r = -0.73, p < .01$ ), and the Moderate group ( $r = -0.64, p < .01$ ). Both statistically and conceptually the Malaise Inventory and Mental Health Inventory appeared to assess somewhat different aspects of maternal distress, therefore separate analyses were conducted for each measure.

The demographic variables (i.e., child characteristics, family characteristics, service/support characteristics) were examined for relationships to the predictor and outcome variables using parametric and non-parametric measures of association. Variables with non-significant associations (Pearson or Spearman correlations:  $p > .05$ ) were not included in further analyses.

The data were analysed using correlation analyses,  $t$ -tests, and regression analyses. Hierarchical multiple regression was used to examine the independent effects of, and proportion of variance explained by the sets of demographic variables, child functional status, and parent-staff interactions on the variance in mothers' levels of psychological and physical symptoms of distress.

## CHAPTER III

### RESULTS

#### Correlations of Demographic Variables with Predictor and Outcome Variables

Associations between the demographic variables and the predictor and outcome variables were examined for the total sample (Table 6), Low group (Table 7) and the Moderate group (Table 8). Of the child demographic variables, the age at which the child was diagnosed and the child's status at CRC (i.e., attends a school program vs. receives out-patient services) were significantly associated with predictor and outcome variables for the total sample.

The age at which a child was diagnosed, and the child's status at CRC were significantly associated with the child's level of functional ability for the total sample ( $r=0.34, p<.05$ ; and  $r = 0.45, p<.01$  respectively) (Table 6). These associations indicate that the more severely impaired children in this sample were more likely to be diagnosed earlier, and were more likely to attend a CRC school program, than were children with mild functional impairments. A child's status at CRC was also significantly associated with maternal symptoms of psychological distress for the total sample ( $\beta = -0.36, p <.05$ ) and the Low group ( $\beta = -0.51, p <.05$ ). These results suggest that participants whose children were in one of the CRC school programs experienced fewer symptoms of psychological distress, than did participants whose children received out-patient services.

The family status variable (i.e., one or two parents) was significantly associated with the level of support in parent-staff interactions ( $r=-0.52, p<.05$ ) for the Low group. Single mothers of severely impaired children were more likely to report higher support from CRC staff, than were mothers in a two-parent partnership.

**Table 6**  
**Demographic Variables Correlated with Predictor and Outcome Variables (N=37)**

	EPS <sup>a</sup>	Vineland <sup>b</sup> ABC	MHI-Index <sup>c</sup>	MI <sup>d</sup>
<b>Child Variables</b>				
Sex	0.24	0.30	0.20	-0.14
Age (in months)	0.01	0.13	-0.08	0.04
Age at diagnosis (in months)	0.01	0.34*	0.02	0.01
CRC Status <sup>e</sup>	0.04	0.45**	-0.36*	0.17
<b>Family Variables</b>				
Family Status <sup>f</sup>	-0.18	0.08	-0.20	0.07
Number of children	0.17	0.11	-0.03	0.07
SES	-0.12	0.08	0.20	-0.09
<b>Service/Support Variables</b>				
Length of time at CRC	0.13	0.02	.010	-0.03
Number of services received from CRC	0.04	-0.46**	0.23	-0.17
Meetings with CRC staff	-0.21	-0.07	0.05	-0.07
Number of services received from other resources	0.06	-0.16	0.08	-0.11
Support from other resources (hrs per week)	-0.21	-0.23	-0.10	0.00
Accessibility of respite care <sup>g</sup>	-0.14	-0.24	-0.13	0.16
Availability of respite care <sup>h</sup>	-0.08	-0.20	0.00	0.14

\*  $p < .05$

\*\*  $p < .01$

<sup>a</sup> High scores indicate more positive perceptions of parent-staff interactions

<sup>b</sup> Vineland Adaptive Behavior Composite score; Low  $\leq 69$ , Moderate-Low 70-84, Adequate 85- 115, Moderate-High 116-130, High  $\geq 131$

<sup>c</sup> High scores indicate fewer symptoms of psychological distress, and greater psychological well-being

<sup>d</sup> 5+ indicates a high level of stress; normative data based on sample of mothers of children with disabilities

<sup>e</sup> 1=school, 2=out-patient

<sup>f</sup> 1=two-parent, 2 = single parent

<sup>g</sup> Low scores indicate greater accessibility

<sup>h</sup> Low scores indicate greater availability



**Table 7**  
**Demographic Variables Correlated with Predictor and Outcome Variables (Low, n=20)**

	EPS <sup>a</sup>	Vineland <sup>b</sup> ABC	MHI-Index <sup>c</sup>	MI <sup>d</sup>
<b>Child Variables</b>				
Sex	0.23	0.15	0.06	-0.01
Age (in months)	-0.02	0.04	-0.10	-0.10
Age at diagnosis (in months)	0.14	0.34	-0.08	-0.06
CRC Status <sup>e</sup>	-0.03	0.34	-0.51*	0.15
<b>Family Variables</b>				
Family Status <sup>f</sup>	-0.52*	0.04	-0.23	-0.01
Number of children	0.04	0.15	0.06	-0.01
SES	-0.29	0.02	-0.29	0.18
<b>Service/Support Variables</b>				
Length of time at CRC	0.16	-0.14	0.08	-0.07
Number of services received from CRC	0.18	-0.20	0.32	-0.36
Meetings with CRC staff	-0.12	0.06	-0.05	-0.12
Number of services received from other resources	-0.22	-0.20	0.01	-0.03
Support from other resources (hrs per week)	-0.20	-0.09	-0.25	0.09
Accessibility of respite care <sup>g</sup>	-0.16	0.03	-0.12	0.05
Availability of respite care <sup>h</sup>	-0.18	-0.25	0.15	-0.09

\*  $p < .05$

<sup>a</sup> High scores indicate more positive perceptions of parent-staff interactions

<sup>b</sup> Vineland Adaptive Behavior Composite score; Low  $\leq 69$ , Moderate-Low 70-84, Adequate 85- 115, Moderate-High 116-130, High  $> 131$

<sup>c</sup> High scores indicate fewer symptoms of psychological distress, and greater psychological well-being

<sup>d</sup> 5+ indicates a high level of stress; normative data based on sample of mothers of children with disabilities

<sup>e</sup> 1=school, 2=out-patient

<sup>f</sup> 1=two-parent, 2 = single parent

<sup>g</sup> Low scores indicate greater accessibility

<sup>h</sup> Low scores indicate greater availability

**Table 8**  
**Demographic Variables Correlated with Predictor and Outcome Variables (Moderate, n=17)**

	EPS <sup>a</sup>	Vineland <sup>b</sup> ABC	MHI-Index <sup>c</sup>	MI <sup>d</sup>
<b>Child Variables</b>				
Sex	0.12	0.21	0.46	-0.45
Age (in months)	0.06	0.32	-0.05	0.29
Age at diagnosis (in months)	0.20	0.14	0.11	0.01
CRC Status <sup>e</sup>	-0.16	0.30	-0.26	0.15
<b>Family Variables</b>				
Family Status <sup>f</sup>	0.18	0.10	-0.16	0.19
Number of children	0.25	0.03	-0.10	0.17
SES	-0.32	-0.05	-0.27	0.09
<b>Service/Support Variables</b>				
Length of time at CRC	0.19	0.34	0.12	0.09
Number of services received from CRC	0.15	-0.39	0.12	0.13
Meetings with CRC staff	-0.44	0.36	0.21	-0.01
Number of services received from other resources	0.18	-0.40	0.18	-0.26
Support from other resources (hrs per week)	0.14	-0.36	0.16	-0.35
Accessibility of respite care <sup>g</sup>	-0.08	-0.57*	-0.18	0.47
Availability of respite care <sup>h</sup>	-0.02	-0.53*	-0.15	0.54*

\*  $p < .05$

<sup>a</sup> High scores indicate more positive perceptions of parent-staff interactions

<sup>b</sup> Vineland Adaptive Behavior Composite score; Low  $\leq 69$ , Moderate-Low 70-84, Adequate 85-115, Moderate-High 116-130, High  $\geq 131$

<sup>c</sup> High scores indicate fewer symptoms of psychological distress, and greater psychological well-being

<sup>d</sup> 5+ indicates a high level of stress; normative data based on sample of mothers of children with disabilities

<sup>e</sup> 1=school, 2=out-patient

<sup>f</sup> 1=two-parent, 2 = single parent

<sup>g</sup> Low scores indicate greater accessibility

<sup>h</sup> Low scores indicate greater availability

Of the services and support variables, the number of services that a child received from CRC was negatively associated with the child's level of functional ability for the total sample ( $r = -0.46, p < .01$ ). This finding suggests that children with more severe functional limitations receive a higher number of services at CRC, in comparison to children with less disabling conditions. A *t*-test yielded a significant mean difference in the number of services received from CRC between the two groups,  $t(35) 2.41, p < .05$ , which indicates that more severely impaired children in this sample received more services from CRC, than did the children with higher functional abilities.

A child's functional ability was also significantly associated with the accessibility  $\beta = -0.57, p < .01$  and availability  $\beta = -0.53, p < .05$  of respite for the Moderate group. These results indicate that mothers of children with severely disabling conditions were more likely to have difficulty finding and maintaining adequate respite care, than were mothers of children with mild impairments. The availability of respite care was also significantly associated with maternal physical symptoms of distress  $\beta = 0.54, p < .05$ , which suggests that mothers who do not have adequate respite care are more likely to experience physical symptoms of stress, than are mothers who report adequate respite care.

### Descriptive Statistics of Predictor and Outcome Variables

The reported level of support in parent-staff interactions for this sample was within one standard deviation of the normative sample mean (Table 9), indicating that mothers in this sample perceive the amount of support from CRC staff as adequate. The results for both the Low and Moderate groups are similar, suggesting that participants experienced a consistent level of

**Table 9**  
**Descriptive Statistics and Normative Data for Predictor and Outcome Variables**

	CRC Sample			Normative Data	
	<u>M</u>	<u>SD</u>	<u>Range</u>	<u>M</u>	<u>S.D.</u>
<b><u>Predictor Variables</u></b>					
Vineland ABC <sup>a</sup>	70.4	15.8	50-140		
Enabling Practices Scale <sup>b</sup> :					
Total Score	98.9	11.3	75-118	87.5	16.5
<b><u>Outcome Variables</u></b>					
Mental Health Inventory					
Index Score <sup>c</sup>	68.4	16.1	22-91	74.2	13.7
Global Scores:					
Psychological distress <sup>d</sup>	27.0	14.4	0-64	20.0	13.0
Psychological well-being <sup>e</sup>	57.6	18.5	10-87	64.4	17.4
Malaise Inventory <sup>f</sup>	5.2	3.7	0-16	4.3	3.6

<sup>a</sup> Vineland Adaptive Behavior Composite score; Low ≤ 69, Moderate-Low 70-84, Adequate 85- 115, Moderate-High 116-130, High ≥ 131

<sup>b</sup> High scores indicate more positive perceptions of parent-staff interactions

<sup>c</sup> High scores indicate fewer symptoms of psychological distress, and greater psychological well-being

<sup>d</sup> High scores indicate a high level of psychological distress

<sup>e</sup> High scores indicate a high level of psychological well-being

<sup>f</sup> 5+ indicates a high level of stress; normative data based on sample of mothers of children with disabilities

support from CRC staff across groups (Table 10). The normative data for the Enabling Practices sub-scales are not available, however, to explore possible differences between groups, the means and standard deviations were calculated for the Low and Moderate groups. The difference in the perceived level of collaboration with CRC staff was significantly different for the Low and Moderate groups,  $t(35) = -2.63, p < .05$ , indicating that participants with more severely impaired children reported a lower level of collaboration with CRC staff regarding their children's care, than did participants with less severely impaired children. The difference in the degree of reported comfort in parent-staff interactions between the Low and Moderate groups approached significance,  $t(35) = -1.86, p = 0.07$ , which suggests that participants whose children were more severely impaired were more likely to report a low level of comfort in their interactions with CRC staff, than were participants whose children were less severely impaired.

Participants scored within one standard deviation of the normative mean on the Mental Health Inventory Index score for the total sample (Table 9), as well as for the Low and Moderate groups (Table 10). These findings indicate that this sample experienced levels of psychological symptoms of distress and psychological well-being that were similar to that of the general population.

The mean level of physical symptoms of distress was within one standard deviation of the normative data for the total sample, as well as for the two groups. However, scoring information for the Malaise Inventory indicates that a score at or above five suggests the respondent is experiencing a high level of distress. The total sample, as well as the two groups, reported approximately five or more symptoms of stress, suggesting that the majority of participants experienced a high level of physical distress.

**Table 10**  
**Descriptive Statistics for Predictor and Outcome Variables by Group**

	Low (n=20)		Moderate (n=17)		t	p
	M	SD	M	SD		
<b>Predictor Variables</b>						
Vineland ABC <sup>a</sup>	61.5	6.0	80.9	17.4	-4.6	.00*
<b>Enabling Practices Scale<sup>b</sup></b>						
Total Score	96.0	10.8	102.3	11.3	-1.7	.10
Comfort in relationship	57.2	6.3	60.9	5.6	-1.7	.07
Collaboration	23.4	3.8	26.3	2.6	-2.6	.05*
Parental autonomy	15.5	2.6	16.7	2.5	-1.5	.14
<b>Outcome Variables</b>						
<b>Mental Health Inventory</b>						
Index Score <sup>c</sup>	69.3	16.6	67.3	16.1	0.4	.71
Psychological distress <sup>d</sup>	27.1	14.5	27.0	14.6	0.0	.99
Psychological well-being <sup>e</sup>	60.7	18.5	54.0	18.4	1.1	.28
Malaise Inventory <sup>f</sup>	4.9	4.5	5.6	3.2	-0.6	.58

<sup>a</sup> Vineland Adaptive Behavior Composite score; Low ≤ 69, Moderate ≥ 70

<sup>b</sup> High scores indicate more positive perceptions of parent-staff interactions

<sup>c</sup> High scores indicate fewer symptoms of psychological distress, and greater psychological well-being

<sup>d</sup> High scores indicate a high level of psychological distress

<sup>e</sup> High scores indicate a high level of psychological well-being

<sup>f</sup> 5+ indicates a high level of stress; normative data based on sample of mothers of children with disabilities

\* p < .05

### **Hypothesis 1- Supportive Parent-Professional Interactions.**

It was proposed that the level of support in parent-staff interactions would be associated with maternal distress. Separate Pearson product moment correlations, and partial correlations, were conducted for each measure of maternal distress. Perceived support from parent-staff interactions was not significantly related to maternal distress in this sample, or in the Low and Moderate groups (Table 11). Partial correlations yielded similar non-significant results.

The second part of Hypothesis 1 stated that when maternal distress was primarily due to child characteristics (e.g., level of adaptability, level of distractability), as opposed to other sources of stress (e.g., parent characteristics such as financial strain or marital discord; life events such as a divorce or job loss), the association between parent-staff interactions and maternal distress would be stronger. The three domains of the Parenting Stress Index (PSI) were used to examine the primary source of stress for this sample. The descriptive scores for the total sample and the normative scores are summarized in Table 12, and the descriptive scores are presented by group in Table 13.

The level of support in parent-staff interactions was not associated with maternal distress for this sample, therefore it was not possible to make a comparison of the degree of association based on the two potential sources of maternal distress. It is interesting to note that more of the mothers in this sample had higher scores on the child domain ( $n=33$ ), than on either the parent or life stress domains. There were three mothers who scored higher on either the parent or life stress domains, and one participant did not complete the PSI. Overall, this finding suggests that child characteristics were a primary source of stress for the majority of mothers in this sample.

**Table 11**  
**Correlations Between Enabling Practices Scale and Distress Scores by Group**

	<b><u>Enabling Practices Total Score</u></b>					
	<b><u>Total Sample</u></b>		<b><u>Low Group</u></b>		<b><u>Moderate Group</u></b>	
	<b><u>r</u></b>	<b><u>p</u></b>	<b><u>r</u></b>	<b><u>p</u></b>	<b><u>r</u></b>	<b><u>p</u></b>
<b><u>Pearson Product Moment Correlations</u></b>						
Mental Health Index Score	0.88	.60	0.13	.59	0.09	.73
Malaise Inventory Score	0.14	.41	0.13	.58	0.10	.69
<b><u>Partial Correlations</u></b>						
Mental Health Index Score <sup>a</sup>	0.12	.53	0.09	.70		
Malaise Inventory Score <sup>b</sup>					0.24	.42

<sup>a</sup> Controlled for CRC status (Total N, Low); Family status (Low)  
<sup>b</sup> Controlled for availability of respite



**Table 12**  
**Descriptive Statistics and Normative Data for the Parenting Stress Index**

	CRC Sample			Normative Data <sup>a</sup>	
	<u>M</u>	<u>SD</u>	Range	<u>M</u>	<u>SD</u>
PSI - Child Domain	120.9	24.3	79-170	97.0-103.0	16.0-21.0
PSI - Parent Domain	125.0	23.2	87-192	116.0-129.0	21.0-27.0
PSI - Life Events	9.1	10.6	0-45		

<sup>a</sup> A range of mean and standard deviation scores were given for normative data

**N.B.** PSI = Parenting Stress Index  
 Higher scores indicate more stress  
 PSI scales based on  $n=35$

**Table 13**  
**Descriptive Statistics for the Parenting Stress Index by Group**

	Low		Moderate		t	p
	M	SD	M	SD		
<b>PSI Domain Scores</b>						
Child Domain	125.6	24.7	116.1	23.2	1.00	.33
Parent Domain	132.8	23.6	116.3	19.3	2.12	.04*
Life Events	10.1	12.5	7.9	8.2	0.62	.54
<b>PSI Sub-scale Score</b>						
Child - Isolation	14.0	3.8	11.5	3.2	2.11	.04*

\*  $p < .05$

**N.B.** PSI = Parenting Stress Index  
 Higher scores indicate more stress  
 PSI scales based on  $n$

In general, the total sample scores on the PSI domains were within one standard deviation of the scores of the general population. However, the average Child Domain score of the Low group was two standard deviations above the general population, which indicates that in this sample, the mothers of more severely impaired children experienced a high level of stress due to their children's characteristics (Table 13). Participants in the Low group reported a higher level of stress in the Parent Domain and the Life Events Domain, in comparison to the Moderate group, which suggests that the mothers of more severely disabled children experienced higher levels of overall stress. A *t*-test indicated a further difference between groups on the PSI Parent Domain sub-scale Isolation,  $t(34) = 2.11, p < .05$ . This result indicates that mothers of children with severe functional impairments felt more isolated than did mothers of children with mild functional impairments.

### Hypothesis 2 -Child Functional Status.

The second hypothesis proposed an association between the level of maternal distress and the level of child functional ability. Separate Pearson product moment correlations and partial correlations were conducted for each measure of distress. The associations did not reach significance for either measure of maternal distress for the total sample (Table 14).

A *t*-test indicated a significant difference between groups on the level of child functional status,  $t(35) = -4.69, p < .01$ . Separate Pearson correlation analyses were conducted between child functional status and maternal distress for each group. As indicated in Table 14, participants in the Low group whose children were more severely impaired were more likely to report fewer symptoms of psychological distress, than were mothers of less severely impaired children in the

**Table 14**  
**Correlations Between Vineland ABC and Distress Scores by Group**

	<u>Vineland Adaptive Behavior Composite Score</u>					
	<u>Total Sample</u>		<u>Low Group</u>		<u>Moderate Group</u>	
	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>	<u>r</u>	<u>p</u>
<b><u>Pearson Product Moment Correlations</u></b>						
Mental Health Index Score <sup>a</sup>	0.01	.96	-0.47	.05*	0.30	.25
Malaise Inventory Score <sup>b</sup>	-0.07	.68	0.28	.24	-0.45	.07
<b><u>Partial Correlations</u></b>						
Mental Health Index Score <sup>a</sup>	0.20	.23	-0.38	.12	0.19	.54
Malaise Inventory Score <sup>b</sup>	-0.21	.23			-0.34	.28

<sup>a</sup> Controlled for CRC status (Total N, Low); number of services from CRC and age at diagnosis (Total N); accessibility and availability of respite (Moderate)

<sup>b</sup> Controlled for CRC status (Total N, Low); number of services from CRC and age at diagnosis (Total N)

\*p<.05

Low group  $\beta = -0.47, p < .01$ ). A partial correlation analysis, controlling for the demographic variables associated with the predictor variable (i.e., child's age at time of diagnosis, number of services family receives from CRC, and child's CRC status), did not yield significant results.

### Hypothesis 3 - Predictors of Maternal Distress.

It was proposed in Hypothesis 3 that maternal distress was more strongly related to the level of child functional status, than to the level of support in parent-staff interactions. This relationship was proposed to exist after controlling for potentially confounding demographic variables (i.e., child, family or service/support variables that were significantly associated with either the predictor or outcome variables). Two hierarchical multiple regression analyses were performed to examine this relationship.

The Mental Health Inventory Index score was entered as the outcome variable in the first regression analysis. The demographic variables were entered first as a set (i.e., age at diagnosis, number of services from CRC, and child's CRC status). In the second set the two predictor variables (i.e., child functional status and support in parent-staff interactions) were entered together. The results, which are summarized in Table 15, indicate that neither the demographic variables, nor the predictor variables, were significant predictors of maternal psychological distress.

In the second hierarchical multiple regression analysis the Malaise Inventory total score was the outcome variable. The demographic variables (i.e., child's status at CRC, child's age at diagnosis, family status, availability and accessibility of respite, number of services from CRC, and child's status at CRC) were entered as the first set to control for possible confounding

**Table 15**  
**Hierarchical Regression Analyses Predicting Maternal Distress**

Predictors	Beta	R <sup>2</sup>	Adj R <sup>2</sup>	R <sup>2</sup> Change	df	F	p
<b>Maternal Distress Measure: Mental Health Index</b>							
Step 1		0.16	0.08	0.16	3,32	2.04	n.s.
Child's age at diagnosis	0.09						
Number of services at CRC	-0.01						
Child status at CRC	-0.44						
Step 2		0.20	0.07	0.04	5,30	1.49	n.s.
Child's age at diagnosis	0.14						
Number of services at CRC	0.05						
Child status at CRC	-0.49						
Support from professionals	0.07						
Child Functional Status	0.21						
<b>Maternal Distress Measure: Malaise Inventory</b>							
Step 1		0.04	-0.05	0.04	3, 32	0.46	n.s.
Child's age at diagnosis	-0.05						
Number of services at CRC	-0.08						
Child status at CRC	0.16						
Step 2		0.12	-0.02	0.08	5, 30	0.84	n.s.
Child's age at diagnosis	0.03						
Number of services at CRC	-0.21						
Child status at CRC	0.20						
Support from professionals	0.20						
Child Functional Status	-0.32						

effects. The two predictor variables were entered together in the second set. As summarized in Table 15, there were no significant predictors of maternal physical symptoms of distress.

## CHAPTER IV

### DISCUSSION

The primary goal of this study was to establish whether the current changes in health care service delivery (e.g., shift toward family-centred practices) effectively address the distress associated with the daily care-giving burden experienced by mothers of children with developmental disabilities. It was necessary to first establish whether the nature of parent-staff interactions was associated with maternal distress, and whether there was a relationship between the functional status of a child with a developmental disability and maternal distress.

#### Hypothesis 1 - Supportive Parent Professional Interactions

It was expected that the principles followed by a family-centred program (i.e., encouraging parental involvement, providing information and support) would enhance participants' abilities to cope with the demands and concerns associated with raising a child with a developmental disability, and thereby reduce maternal distress. However, maternal perceptions of the nature of support received from CRC was not significantly associated with either physical or psychological symptoms of distress for this sample.

The mothers in this sample represented a very small proportion of the population of families who receive services from CRC (12%), which leads to speculation regarding the differences between this sample and the population. The majority of scores on the measure of parent-staff relationships were clustered in the adequate to high range, indicating that for the most part, the participants were satisfied with the level of support they received from CRC. The generally positive relationship these mothers have with the CRC staff may have motivated them to participate in the present research project. The limited range of scores on the measure of



parent-staff interactions reduced the likelihood of a significant association between the predictor and outcome variables.

While the proposed association between parent-staff interactions and maternal distress was not substantiated, the results yield trends which suggest that parent-professional interactions have a role in maternal well-being. An examination of the service and support variables indicated that mothers of children attending the school program experienced fewer symptoms of psychological distress, than did mothers of children receiving out-patient services. The mothers of children in the school program had more opportunities for parent-staff interactions than did mothers of children in the out-patient program. Children in the school program also received a higher level of services from CRC than did the children who received out-patient services, which would also result in more opportunities for connecting with staff. It may be that the greater frequency of contact with staff provided mothers of children in the school program opportunities to express their concerns and have their needs addressed, thus reducing maternal distress.

Further support for the role of parent-professional interactions in reducing maternal distress was provided by the association between the level of support from resources other than CRC, and maternal physical symptoms of distress. Mothers of more severely impaired children who had less access to support outside of the rehabilitative setting (i.e., respite care in the home) reported more symptoms of physical distress. This finding suggests that professionals provide some degree of support for the physical demands that these mothers experience. Overall, trends in the results suggest that the level of support, from both CRC and other resources, has a role in the well-being of mothers of children with functional impairments.

## **Hypothesis 2 - Child Functional Status.**

Previous research indicates that mothers of children with low functional abilities cope with a high level of physical and psychological demands on a daily basis. It was expected that participants, whose children had limited functional abilities and required a high level of care, would experience high levels of psychological and physical symptoms of distress. However, the level of child functional status was not significantly associated with maternal distress for the total sample in the present study.

The homogeneity of the children's functional abilities in the present sample suggests a possible explanation for the results. Most children were categorized in the two lowest categories of the five Vineland ABC categories (low adaptive ability,  $n=20$ , moderate-low adaptive ability,  $n=12$ ), which indicates that the majority of children in this sample experienced substantial functional impairment. The limited range of functional status scores reduced the potential for uncovering an association between functional status and distress.

Within the Low group, mothers of more severely impaired children reported significantly fewer psychological symptoms of distress than did mothers of less severely impaired children. The high level of services and support received by mothers of severely impaired children may provide a possible explanation for this result. An examination of the service and support variables indicated that children with severe functional impairments generally received a high level of intervention, both from CRC (e.g., specialized education and rehabilitative programs) and community resources (e.g., respite services), and subsequently their parents had a high level of contact with health care professionals. The high frequency of contact between mothers and the professionals may foster a supportive relationship that provides emotional support to the

mothers. The emotional support may, in turn, mediate the mothers' concerns regarding their children and thereby reduce psychological symptoms of distress.

The expectations for their children's progress may provide an alternate explanation for the lower levels of perceived psychological distress reported by the mothers of severely impaired children. In comparison to the mothers of moderately impaired children, mothers of severely impaired children may have lower expectations and hopes for their children's functional abilities both on a daily basis, and in terms of their long-term prognosis. As a result, mothers of more severely impaired children may, to some degree, have accepted their children's limitations and the impact of the children's limitations on the family. The mothers' acceptance of their children's limitations, in combination with the high degree of support from health care professionals, may have had the effect of reducing overall psychological symptoms of distress.

Trends in the results provide partial support for the association between maternal distress and child functional status. Group comparisons indicated that mothers of more severely impaired children (i.e., the Low group) identified child characteristics (e.g., adaptability, demandingness) as a greater source of stress than did mothers of less severely impaired children (i.e., the Moderate group). Mothers of children with severe functional impairments also reported experiencing a higher level of social isolation than did mothers of children with moderate functional impairments. In comparison to mothers of children with moderate functional impairments, mothers of children with severe impairments also reported more parent characteristics that contributed to stress in parent-child relationship (e.g., low perceived competence as a parent, sense of isolation) and more stressful life circumstances (e.g., financial

strain, marital discord). Together these findings suggest that the level of a child's functional ability appears to have an impact on the level of stress in the parent-child relationship.

Further examination of trends in the results suggest that child functional status may have an effect on maternal perceptions of parent-staff interactions. Group comparisons indicated that mothers of children with less severe functional impairments (i.e., children in the Moderate group) were more comfortable with parent-staff interactions than were mothers of children in the Low group. The Moderate group also reported a stronger sense of partnership with staff, than did mothers of children in the Low group.

The ability of health care professionals to effectively treat children with profound functional impairments is often more limited than it is for children with mild functional impairments. This difference may have an effect on the mothers' perceptions of their interactions with health care professionals. Additionally, children with profound functional impairments usually have a broad spectrum of highly demanding needs. Health care professionals are often unable to address all aspects of a child's needs, which may have a role in reducing mothers' perceptions of being in a partnership with staff, as they alone are responsible for some aspects of their children's care. Together with the trends that provide support for the association between maternal distress and child functional status, these findings indicate that further research in this area is warranted.

### **Hypothesis 3- Predictors of Maternal Distress**

It was expected that both the level of a child's functional ability and the level of support from professionals would be associated with maternal distress. It was proposed that the high level of burden associated with caring for a child with severe functional impairments would be

the stronger predictor of maternal distress. However, given that neither child functional status, nor parent-staff interactions was significantly associated with maternal distress in the first two hypotheses, it was anticipated that neither variable would be a significant predictor of maternal distress. The results of the two hierarchical multiple regression analyses confirmed this expectation.

There are three methodological limitations of the present study which may have contributed to the failure to fully support the proposed hypotheses, and indicate the need for further investigation. The first concern is with the low response rate. The sample in the present study represented only twelve percent of the available population, which suggests that the respondents may not be representative of the remainder of the population. It may be that, in general, mothers of children with severe functional impairments experience a high level of distress, and because of the high level of demands on their time and energy, very few were able to respond. As a result, only those mothers who were not highly distressed were able to participate.

There may also be other factors that motivated the participants to respond, which leads to the second limitation, the limited range of scores on measure of parent-staff interactions. The majority of respondents reported adequate to high levels of satisfaction in their relationships with the staff at CRC, which may have provided a motivation for them to participate, which, in turn, may have biased the results.

The clustering of functional status scores in the low range represents a third methodological limitation of the present study. The majority of the children in this sample experienced either severe or moderate functional impairments; children with mild, or no

functional impairments were not adequately represented. The limited range of functional status scores restricts the potential for group comparisons, and also indicates that this sample is not representative of the general population, which limits the potential for generalizations.

Trends in the data suggest some clinical implications, and also provide evidence that indirectly supports the initial purposes of this investigation. First, the level of support received from health care services was found to have a role in the emotional well-being of mothers of children with functional impairments. This finding indicates the importance of continued improvement in parent-staff relationships, as well as the importance of continued investigations of the relationship between health care professionals and the primary care-givers of children with developmental disabilities. Second, further investigation into the role of the resources that reduce the impact of the physical demands of daily care-giving (e.g., respite care) is also warranted. Third, the level of stress in parent-child relationships was found to be higher for mothers of children with more severe functional impairments than for mothers of less severely impaired children. This finding suggest that further investigation into the impact of child functional status on parent-child relationships is warranted.

The results of the present study do not fully support the proposed relationships between maternal distress and the predictor variables child functional status and parent-staff interactions. However, the results of previous research provide conceptual support for the predicted relationships, and together with the trends in the present results, indicate that once the methodological limitations of the present study are addressed, further investigation is warranted.

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**Appendix A**  
**Family Information Questionnaire**

**CHILD**

Child's Sex            Male \_\_\_\_      Female \_\_\_\_

Child's Birth Date    \_\_\_\_\_

Child's Grade        \_\_\_\_\_

Child's Age when disability identified    \_\_\_\_\_

Please Describe your Child's Disability    \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**FAMILY**

Number of Children in Your Family \_\_\_\_\_

Birth Order of your Child that Receives Services from CRC (e.g., oldest, middle, youngest)

\_\_\_\_\_

Please Circle the One that Best Describes your Family:

    Single-parent    Two-parent    Other

Highest Grade Achieved by Mother \_\_\_\_\_

Occupation of Mother (Be specific) \_\_\_\_\_

Highest Grade Achieved by Father \_\_\_\_\_

Occupation of Father (Be specific) \_\_\_\_\_

**C.R.C.**

Length of Time your Child has Received Services at C.R.C. \_\_\_\_\_

Type of Services your Child Receives at C.R.C. (Please list all that apply; e.g., day school program, physiotherapy etc.)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How often do you meet with professionals at C.R.C. to discuss your child's care?

\_\_\_\_\_

Do you always see the same professionals at C.R.C.? Please list the title of the professionals you meet with (e.g., physiotherapist, classroom teacher).

\_\_\_\_\_

\_\_\_\_\_

**OTHER RESOURCES**

**Does your Child Receive Services from any Other Resources? (e.g., Infant and Family Program, Respite Services). Please describe and indicate how often.**

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**How easy is it for you to find respite care? (Please circle one).**

<b>Very Easy</b>	<b>Somewhat Easy</b>	<b>O.K.</b>	<b>Somewhat Difficult</b>	<b>Very Difficult</b>
1	2	3	4	5

**How often is respite care available when you need it?**

<b>Always</b>	<b>Sometimes</b>	<b>3</b>	<b>Rarely Never</b>
1	2		4



## Appendix B

### Enabling Practices Scale

Please circle the number that best applies to you. There are no right or wrong answers to these statements. Please be sure to complete both sides!

Example:

	NOT TRUE AT ALL	MOSTLY NOT TRUE	SOMEWHAT TRUE	MOSTLY TRUE	VERY TRUE
I play many sports.	1	2	3	4	5

If the statement applies very much to you, you would circle the **VERY TRUE** number, as shown. If the statement did not apply to you at all, you would circle the **NOT TRUE AT ALL** number. You should circle the other numbers if the statement applies to you in a different way.

**If your child receives services from other health care professionals in addition to the staff at CRC, please only think about the staff at CRC when completing this questionnaire.**

Circle one number in each row

	NOT AT ALL TRUE	MOSTLY NOT TRUE	SOMEWHAT TRUE	MOSTLY TRUE	VERY TRUE
1. The staff and I agree on what is most important in my son's/daughter's program.	1	2	3	4	5
2. It is easy to follow the advice of the staff.	1	2	3	4	5
3. The staff consider my family and friends when discussing my son's/daughter's program.	1	2	3	4	5
4. I am the person who makes the most important decisions about my son's/daughter's program.	1	2	3	4	5
5. The staff's suggestions for working with my son/daughter make me feel comfortable.	1	2	3	4	5

		NOT AT ALL TRUE	MOSTLY NOT TRUE	SOMEWHAT TRUE	MOSTLY TRUE	VERY TRUE
6.	<b>The staff accept our family's values and beliefs.</b>	1	2	3	4	5
7.	<b>I am an equal partner in the relationship I have with the staff.</b>	1	2	3	4	5
8.	<b>Working with the staff has made me feel more capable</b>	1	2	3	4	5
9.	<b>It is easy to work together with the staff when planning my son's/daughter's program.</b>	1	2	3	4	5
10.	<b>I feel I should be given the most credit for the progress my son/daughter makes.</b>	1	2	3	4	5
11	<b>With the support of the staff, I am able to solve problems quickly.</b>	1	2	3	4	5
12	<b>The suggestions that the staff make are positive.</b>	1	2	3	4	5
13.	<b>The staff encourage me to contact my family and friends when I need advice.</b>	1	2	3	4	5
14.	<b>The staff care about my son/daughter and my family.</b>	1	2	3	4	5
15.	<b>The assistance the staff gives meets our family's needs.</b>	1	2	3	4	5
16.	<b>The staff anticipate our family's concerns and needs.</b>	1	2	3	4	5

		NOT AT ALL TRUE	MOSTLY NOT TRUE	SOMEWHAT TRUE	MOSTLY TRUE	VERY TRUE
17.	I am the person most responsible for the important changes in the life of my son/daughter.	1	2	3	4	5
18.	I feel comfortable giving the staff advice if they ask for assistance.	1	2	3	4	5
19.	By following the staff's suggestions I have learned how to deal with family concerns.	1	2	3	4	5
20.	The staff offer help in response to our family's needs.	1	2	3	4	5
21.	I decide the programs for my son/daughter.	1	2	3	4	5
22.	The staff are happy to accept my suggestions.	1	2	3	4	5
23.	I feel that I am able to carry out the suggestions of the staff.	1	2	3	4	5
24.	The staff's suggestions for working with my son/daughter at home produce quick results.	1	2	3	4	5

**Note.** Reprinted with permission of the author, I. Dempsey. Special Education Centre, University of Newcastle, Callaghan, NSW Australia 2308.

**VITA AUCTORIS**

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