Predictors of parent perceptions of well-being for children with neurodevelopmental disorders: The roles of child function and of child and family supports and services

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Table of Contents

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Abstract

Little is known about the factors affecting the well-being of children with neurodevelopmental disorders (NDD). Both child function and supports and services have been found to impact the well-being of parents of children with NDD. The current study had two prime objectives. The first was to examine whether child function and supports and services were also predictive of well-being for children with NDD. The second was to contribute to the research methodology of a larger study through the direct assessment of a subsample of children with NDD.

First, the current project assessed whether child function as well as the adequacy of supports and services provided to children and their families were predictive of child well-being. Well-being was assessed using a measure of quality of life developed for use with children with NDD. Data from 234 parents were included in a structural equation model (SEM) analysis, and each predictor was found to load significantly on the overall outcome variable of well-being. Parent concerns about child function were significantly related to child well-being; parents who reported more concerns about their children's functioning reported lower levels of child well-being. Unmet needs for supports and services were also significantly related to child well-being; parents who reported that more of their children's and family's service needs were unmet reported lower child well-being. An indirect relationship was also found between child function and child well-being. When parents reported that their support needs were adequately met, their children's functional difficulties had a lower impact on parent perceptions of their children's overall well-being.

Second, this study contributed to the research design of the larger study through the direct assessment of a subsample of children. *About My Child, 26-item version* (AMC-26) was developed as a measure of child health complexity and was used in the current study as measure of the number of concerns parents had about their children's functioning. The reliability and validity of AMC-26 was investigated with a sample of 262 parents of children with NDD. A five-factor model explained 45.96% of the variance. Construct validity was tested through associations with relevant subdomains of an existing measure of parent-reported child difficulties and also with the subsample of children (*n* = 49) using standardized measures of cognitive and adaptive functioning. Many predicted relationships were observed, providing support for the reliability and validity of AMC-26 as a parent-report measure of child function. It was further hypothesized that parents' perceptions of their children's functioning would mediate the relationship between children's functioning as assessed by standardized measures of cognitive and adaptive functioning and parent perceptions of their children's well-being. Overall, the results supported this hypothesis. Taken together, the results of the current study enrich our understanding of well-being for children with NDD. Discussion focuses on the service implications for children with NDD and their families.

Résumé

Il existe peu de données au sujet des facteurs qui affectent le bien-être des enfants ayant des troubles neurologiques (TN). Pourtant, plusieurs recherches démontrent que le niveau de fonctionnement de l'enfant ainsi que le niveau de soutien et des services affectent le bien-être des parents d'enfants ayant des TN. La présente étude a deux objectifs prioritaires. Le premier objectif de cette étude vise à examiner si le niveau de fonctionnement de l'enfant et le niveau de soutien et de services ont une valeur prédictive sur le bien-être des enfants ayant des TN. Le second objectif consiste à contribuer à la méthodologie de recherche d'une plus vaste étude grâce à l'évaluation directe d'un sous-échantillon d'enfants.

Premièrement, la présente étude a affirmativement évalué l'impact du niveau de fonctionnement de l'enfant et de l'adéquation entre le niveau du soutien et des services sur le bien-être de l'enfant ayant des TN. Le bien-être de l'enfant a été mesuré selon une échelle de qualité de vie conçue pour les enfants ayant des TN. Les données recueillies auprès de 234 parents ont été analysées en utilisant la modélisation par équations structurelles (SEM). Cette technique statistique SEM a révélé que chacune des variables prédictives a eu une influence significative sur la variable de résultat globale du bien-être. Les préoccupations des parents au sujet du fonctionnement de leur enfant étaient significativement liées au bien-être de l'enfant; ceux qui avaient le plus d'inquiétudes concernant le fonctionnement de leur enfant ont démontré des niveaux de bien-être inférieurs chez l'enfant. De plus, les lacunes au niveau du soutien et des services avaient aussi une importance significative sur le bien-être de l'enfant. Les parents qui rapportaient le plus grand nombre de lacunes au niveau des services à la famille et à leur enfant ont démontré un niveau inférieur de bien-être chez l'enfant. Un lien indirect entre le fonctionnement de l'enfant et son bien-être s'est aussi révélé. Lorsque les parents indiquaient que les soutiens obtenus comblaient leurs besoins, les difficultés de fonctionnement de l'enfant avaient un impact moins important sur le bien-être général de l'enfant perçu par les parents.

Deuxièmement, cette étude a contribué à la méthodologie de recherche de la plus vaste étude grâce à l’évaluation d’un sous-échantillon d’enfants. Afin de recueillir les données, la version de 26 questions de *About My Child* (AMC-26), un outil permettant l’évaluation de la complexité de la santé chez les enfants, a été utilisé pour mesurer le nombre d’inquiétudes des parents au sujet du fonctionnement de l’enfant. La fiabilité et la validité de l’AMC-26 auprès d’un échantillon de 262 parents d’enfants ayant des TN a été analysée. Un modèle à cinq facteurs expliquait 45.96% de la variance. La validité conceptuelle a été vérifiée par des associations avec les sous-domaines pertinents d’une mesure existante signalée par les parents au sujet des difficultés de l’enfant ainsi que par le sous-échantillon d’enfants (*n* = 49) en utilisant les mesures standardisées du fonctionnement cognitif et adaptatif. L’observation de plusieurs relations prévues a soutenu la fiabilité et la validité de l’AMC-26 comme échelle d’évaluation du fonctionnement de l’enfant observée par les parents. De façon générale, les résultats soutiennent l’hypothèse émise que les perceptions des parents à propos du fonctionnement de leur enfant contribueraient à modifier la relation entre le fonctionnement de l’enfant tel qu’évalué selon les mesures standardisées du fonctionnement cognitif et adaptatif, et les perceptions des parents à propos du bien-être de l’enfant. Dans leur ensemble, les résultats de cette étude viennent enrichir nos connaissances au sujet du bien-être des enfants ayant des TN. La discussion se concentre sur l’impact des services sur les enfants ayant des TN et sur leurs familles.

List of Tables

List of Figures

List of Appendices

Chapter 1: Introduction

Problem Statement

As we enter the 21st Century, much attention is directed towards quality control and customer satisfaction. This focus has influenced many spheres of our society, including the health sector in the form of outcome research (McLaughlin & Bjornson, 1998), and more recently in the social services sector in the form of policy development and implementation (Zekovic & Renwick, 2003). The construct of quality of life has been familiar to the medical world for several decades, evolving out of the World Health Organization's (WHO; 1948) definition of health (McLaughlin & Bjornson, 1998). WHO's (1948) definition of health included physical, mental, and social well-being, and also included the absence of disease. Investigations of quality of life that used WHO's definition were health-focused and ignored many aspects of the individual's lived experience that might impact day-to-day well-being (Renwick & Fudge Schormans, 2003). In recent years, social service agencies supporting individuals with neurodevelopmental disorders (NDD) have also begun to examine quality of life issues, shifting their focus from health-related quality of life to more holistic conceptions of this construct (Renwick & Fudge Schormans, 2003). In line with more recent WHO publications (e.g., WHO, 2001, 2002), in which greater emphasis is placed on functioning,[1] new models of child quality of life are emerging that incorporate children's participation in society (Renwick & Fudge Schormans, 2003).

While we are learning more about the particular needs of this special population, much is still unknown. For instance, parents whose children have NDD have repeatedly been found to have significantly higher stress levels (e.g., Dyson, 1997; Hassal, Rose, & McDonald, 2005; Minnes, 1998; Solomon, Ono, Timmer, & Goodlin-Jones, 2008) and poorer physical and psychosocial health (Lach et al., 2009; Miodrag & Hodapp, 2011) than parents with typically developing children. Researchers have shown that the quality of parent-child interactions is central to the development of

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[1] According to the International Classification of Functioning, Disability, and Health (WHO, 2001), functioning involves body functions as well as activities and participation.

children (e.g., Hauser-Cram et al., 2001; Martin & Cole, 1993; Minnes, 1998), and that child functioning impacts parenting behaviour (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Lewis et al., 2006). Yet, little is known about the unique factors affecting parenting behaviour in families with children with NDD. Still less is known about factors affecting the well-being[2] (often assessed via measures of quality of life) of children with NDD, and in particular the role that child functioning might play in children's well-being is still largely uninvestigated and represents a gap in our present understanding. Children with NDD often experience difficulties in one or more areas of functioning (e.g., body functions, activities, or participation). While certain direct services, such as early intervention, have proven effective in ameliorating functioning in children with NDD (e.g., Guralnick, 1997, 2001, 2005, 2008), the role of other supports and services provided throughout childhood, rather than in the early years of child development, is less well understood. Several researchers have found that both formal and informal supports and services can impact the well-being of parents (Ammerman, Hersen, van Hasselt, Lubetsky, & Sieck, 1994; Antshel & Joseph, 2006; Benson, 2012; Boyd, 2002; Burke & Hodapp, 2014; Dyson, 1997; Ebert, Levine, & Zuckerman, 1989; Floyd & Gallagher, 1997; Hassall, Rose, & McDonald, 2005; McConnell, Breitkreuz, & Savage, 2010; Miodrag & Sladeczek, 2009; Nachshen & Minnes, 2005; Poehlmann, Clements, Abbeduto, & Farsad, 2005; Weiss, 2002). However, few studies have examined the impact of supports and services on the well-being of children (e.g., Barakat & Linney, 1992; Collins, Dunkel-Schetter, Lobel, & Scrimshaw, 1993; Perrin, Ayoub, & Willett, 1993), and only a few studies have examined the impact of supports and services on the well-being of children with NDD in particular (Appleton, Ellis, Minchom, Lawson, Böll, & Jones, 1997; Bier, Prince, Tremont, & Msall, 2005; Dunst, Trivette, & Cross, 1986; Rothman & Cosden, 1995). The majority of studies examining children with NDD have focused on forms of NDD in which cognitive functioning is often unimpaired (Appleton et al., 1997; Bier et al., 2005; Rothman & Cosden, 1995),

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[2] McDowell (2010), drawing on Diener, Horwitz, and Emmons (1985), defines well-being as "…contentment, satisfaction, or happiness derived from optimal functioning. This need not imply perfect function; it is subjective and is a relative, rather than an absolute, concept. The reference point for judging well-being is [the] person's own aspirations, based on a blend of objective reality and their subjective reactions to it" (p. 70)

leaving a substantial gap in the literature concerning the impact of supports and services on children with other unaddressed forms of NDD.

Significance of the problem. The expected value of the current research project is to understand better the needs of children with NDD and their families and then to inform public policy and practice. The focus of the current investigation is on child well-being as a correlate of level of functioning, rather than diagnosis. A non-categorical (cross-diagnostic) approach was chosen, as there is increasing support for the assumption that child function affects parenting more than diagnosis (Abbeduto et al., 2004; Azad, Blacher, & Marcoulides, 2013; Eisenhower, Baker, & Blacher, 2009; Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006; Lewis et al., 2006; Neece, Green, & Baker, 2012). Similarly, there is support from both quantitative and qualitative investigations for the notion that there is more variability within disabilities than between them. It may therefore be more meaningful to look at the construct of child function, rather than diagnosis, when examining child well-being (Gannoni & Shute, 2010; King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006; Ronen & Rosenbaum, 2013; Simeonsson, Leonardi, Lollar, Bjorck-Akesson, Hollenweger, & Martinuzzi, 2003). Therefore, the current study includes children with a variety of NDD including (but not limited to) autism spectrum disorder, cerebral palsy, Down syndrome, developmental disability, epilepsy, global developmental delay, and genetic and metabolic conditions. Expanding upon the findings from existing noncategorical studies, the current research aims to assess whether level of function is also predictive of well-being for children with NDD. Recent studies have examined child function as a predictor of well-being in children with physical disabilities (Law et al., 2004), Duchenne muscular dystrophy (McDonald et al., 2010), developmental coordination disorder (Zwicker, Harris, & Klassen, 2012), chronic medical problems (Payot & Barrington, 2011), Dravet syndrome (Brunklaus, Dorris, & Zuberi, 2011), and Asperger syndrome (Cederlund, Hagberg, & Gillberg, 2010). Thus, the majority of studies have investigated conditions of a more physical or medical nature, or high-functioning forms of NDD. Empirical data are therefore required to determine whether function also significantly impacts the well-being of children with a range of NDD. Such data are required in order to inform public policy decisions, which are often implemented across diagnostic aetiologies of childhood disability, rather than being targeted to specific diagnostic groups (Ronen, Fayed, & Rosenbaum, 2011). To date, no cross-diagnostic studies have examined child function as a possible predictor of well-being in children with NDD. Therefore, this component of the research project will contribute valuable information that will help to guide service development and implementation.

In terms of supports and services, the present study builds upon existing research that shows that access to supports and services positively impacts parent well-being (e.g., Antshel & Joseph, 2006; Hassall et al., 2005; Miodrag & Sladeczek, 2009; Nachshen & Minnes, 2005; Poehlmann et al., 2005; Weiss, 2002), and aims to explore the extent to which access to supports and services is related to child well-being. As described above, current understanding of the factors impacting the well-being of children with NDD is poor. In order to inform policy and practice we need to understand better the ways in which supports and services provided to children and their families impact the lives of children with NDD. Greater insight into this relationship will be important for securing access to necessary supports and services and in so doing, promoting the well-being of children with NDD.

In addition to its intrinsic benefits, this study contributes to a larger mixed methodology project led by Dr. Lucyna Lach and her colleagues: *the CIHR Team in PARENTING MATTERS! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada* (Funding reference number: CWC94790). The larger mixed-methods project involves both quantitative and qualitative data collected from mothers and fathers of children with NDD. Rich information will be drawn from these families and the current project adds to the integrated design of the larger study by directly assessing child function with a subsample of children. Many studies examining children with NDD use parent report measures as the primary sources of information on child functioning. One reason for this is that assessment with children with NDD can be more challenging than assessment with typically functioning children and often requires considerable time commitment. By using a standardized assessment of cognitive functioning of children with NDD, the current study contributes another dimension and adds to the picture of child function. This study also adds a measure of adaptive functioning, conducted in interview form with parents. If parent reports of their children's functioning are found to be commensurate with the results of the standardized direct assessment, this will support the use of parent-report measures of child functioning in research with children with NDD. However, if the current investigation reveals that parent reports and standardized assessments differ in their results this will serve to inform current research practice that relies heavily on parent-report measures. In either case, both the direct cognitive assessment and the adaptive interview provide an important complement to the existing methodology of the Parenting Matters! project. Furthermore, the parent-report measure of child function is currently undergoing validation by its developers. As part of the current study the reliability and validity of the measure will be tested using data obtained from the cognitive and adaptive assessments done with the subsample of families. If evidence of reliability and validity is obtained, this will support further use of the parent-report tool.

Theoretical Framework

The current study draws on the International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY; WHO, 2007) as well as Bronfenbrenner's (1977; 1979; 1986) ecological model of human development and its more recent conceptualization, the bioecological model (Bronfenbrenner, 2001; 2005; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 1998). These theoretical frameworks serve to guide and inform the research design and hypotheses of the research project. Both frameworks are briefly outlined in the following section.

The International Classification of Functioning, Disability and Health (ICF; WHO, 2001), is a set of guidelines for categorizing issues relating to disability, which places an emphasis on health and functioning, rather than on disability and disease. According to this classification, functioning is defined as “all body functions, activities and participation” (WHO, 2002), whereas disability is used to refer to dysfunction at the level of impairments, activity limitations, or participation restrictions (WHO, 2002). Given that disability is in part defined by health conditions but also by the environment, which includes the physical environment, services available, as well as attitudes and legislation, only a framework that considers all of these interacting components can hope to accurately characterize the construct of disability. Thus, the ICF is based on a biopsychosocial model of disability that combines both medical and social aspects of disability (Dahl, 2002).

The ICF is divided into four chapters: body function, body structure, activities and participation, and environmental factors. Each chapter outlines qualifiers that specify the presence and severity of a problem in functioning at the body, person, or societal level (WHO, 2002). Body functions are conceptualized by the ICF as the physiological functions of the body, and they include cognitive functions. Body structures are the physical structures of the body, and include organs, limbs, and their respective components. Activities and participation, while grouped together in one chapter, represent separate and distinct constructs. The core element of activity is that of the execution of behaviour. The core element of participation, on the other hand, is that of engagement in a particular situation. For activity, the ICF provides a capacity qualifier, which deals with the individual’s ability to perform a task or behaviour unassisted. The qualifier for participation is referred to as a performance qualifier, and it deals with the extent to which an individual is restricted from engaging in activities, or the individual’s “lived experience” (WHO, 2003). Finally, the ICF’s environmental factors chapter addresses the physical, social, and attitudinal environment.

The International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY; WHO, 2007) is derived from the ICF and has as its purpose the classification of those characteristics that are specific to developing children as well as the influences of children’s surrounding environments. Like the ICF, the ICF-CY provides clinicians, educators, researchers, policy makers, and parents with a common universal language with which to document and measure child health and disability. The ICF-CY arose from a need to understand the unique developmental needs of children and adolescents that are different from adults. For instance, the ICF-CY recognizes that child development is a dynamic process that is dependent on the children's interactions with caregivers and the environment. In terms of skills acquisition and overall child functioning, the interactions children have with their caregivers and their environments can directly impact their development. The ICF-CY also specifies the role that developmental delays can play in the health of children and youth. This component is unique to the ICF-CY as children and adolescents may experience delays in their development that may not persist into adulthood. In addition, the children and youth version recognizes that the severity of the qualifier codes may therefore change over time as children develop. Given the influence that children's caregivers and environments play in their development, the ICF-CY recognizes that children's opportunities to participate are also dependent on their parents, caregivers, and service providers. The ICF-CY identifies the importance of understanding the roles that these individuals play in children's lives in order to accurately understand the nature of children's participation. Finally, the ICF-CY conceptualization of children's environments accounts for the unique factors that affect children and adolescents. Over the course of their development, children's environments undergo numerous changes, both in terms of the nature and the complexity of the environments. Compared to adults, negative environmental factors can have a greater influence on children (WHO, 2007). Therefore, the ICF-CY states that for children, intervention for and prevention of negative health outcomes should include the modification of the children's physical, social, and psychological environments.

The ICF and ICF-CY were both developed with the aim of providing integrated and dynamic frameworks for researchers, clinicians, and individuals to use in the service of individuals with disabilities. Fayed and her colleagues (Fayed, 2011; Fayed, Cieza, & Bickenbach, 2011; Fayed, Schiariti, Bostan, Cieza, & Klassen, 2011; Schiariti, Fayed, Cieza, Klassen, & O'Donnell, 2011) systematically examined measures of health status and health-related quality of life (QoL) using the ICF as well as WHO definitions of health status and QoL. These investigators found that studies frequently reported using the same measures to capture information about different issues or conversely, using different measures to examine the same underlying construct (Fayed, 2011). Both scenarios are problematic and, Fayed suggests, could easily be resolved with the use of a common unifying framework like the ICF. The ICF is thus increasingly seen as an important tool to guide researchers so that all are using the same language (Schiariti et al., 2011).

With the emphasis on function, rather than disability, “the classification [can be used] to obtain systematic information about a person’s functioning [and] can provide professionals with relevant information and can guide the selection of interventions” (Dahl, 2002). As outlined in the ICF Training Beginner’s Guide, a central aim of the classification is to facilitate the identification of gaps between capacity and performance and also between needs and services (WHO, 2002). It is with these intervention objectives in mind that the current study draws on the ICF. By using the ICF as a common organizing tool, service providers can work with parents and children to discuss each individual’s priorities for intervention and to set treatment goals (Kraus de Camargo & Fayed, 2013). The present investigation uses the classification’s definitions of both functioning and participation, and aims to identify the possible gaps that exist in the lives of families of children with NDD in order to clarify their particular service needs. Furthermore, the present author draws on the works of researchers such as Fayed and her colleagues who stipulate the importance of looking not only at function, but also at individuals’ perceptions of their participation and well-being (Fayed, 2011; Fayed, Schiariti, et al., 2011). Such a focus is important because, as Fayed argues, a child who gives a low rating to her functional ability in one area may at the same time evaluate that particular functional limitation to be of low importance and assess it as having a negligible impact on her well-being. A measure that asks only questions about function cannot then be compared to a measure that asks only questions of perception.

The ICF-CY provides additional guidance as it specifies the particular needs of children and adolescents, whose development is dependent upon the individuals with whom they interact as well as upon their environments. The stipulation in the ICF-CY that “alteration of the social and psychological elements of the child’s immediate environment may involve social support for the family and education for caregivers" (WHO, 2007) is particularly relevant to the project. On a broader level, the ICF-CY's guideline that systems not immediately impacting children may also require intervention at the level of legislation or national policies to protect the well-being of children with disabilities, is also of import to the current study.

Bronfenbrenner's (1977; 1979; 1986) ecological model of human development suggests that human development occurs within a nested system. According to this model there are four interconnected systems interacting with individuals over the course of their lifelong development: the microsystem, the mesosystem, the exosystem, and the macrosystem (Bronfenbrenner, 1977). The microsystem involves individuals and their immediate settings, that is, environments with specific characteristics in which people have set roles and operate within set periods of time. The mesosystem is a system of microsystems, it encompasses all of the interrelationships between individuals' environments. The exosystem includes all of those settings that surround the mesosystem, such as neighbourhoods, workplaces, and governmental services and supports. Finally, the macrosystem refers not to a specific setting but to an overarching framework, one which often includes both implicit and explicit rules and regulations.

Bronfenbrenner (1979) proposed that third parties (beyond the parent-child dyad) play a key role in children's development by either supporting or undermining the actions of those individuals who engage with children directly. Recent research findings suggest that informal social support does predict depressive symptoms in mothers of children with Down syndrome and autism/PDD-NOS, with mothers who had fewer depressive symptoms reporting higher levels of social support (Miodrag & Sladeczek, 2009) and that characteristics of the social support networks (e.g., size and amount of support given) are also significantly related to maternal depressive symptoms for mothers of children with ASD (Benson, 2012). Bronfenbrenner went on to state that the existence of supportive networks around children and their parents positively impact development. The addition of supports would act in an additive way such that "the developmental potential of a child-rearing setting is increased as a function of the number of supportive links" (Bronfenbrenner, 1979).

In a review of the research literature supporting an ecological model of development, Bronfenbrenner (1986) concluded that social support might be most effective in conditions in which a certain amount of stress is present. However, if too much stress exists in the developmental environment, social support may be ineffective. In such instances the family's need for formal support may be higher and the level of stress may only be ameliorated when access to and use of formal supports and services occurs. Conversely, some researchers have shown that informal support may act as an effective mediator of stress, such that more formal supports may not be necessary when sufficient informal support is present (Dunst et al., 1986; Gourash, 1978). In their mixed methods study of mothers and fathers of individuals with intellectual disabilities (*n* = 34 families), Brown, Anand, Fung, Isaacs, & Baum (2003) interviewed parents regarding their family quality of life. The majority of parents reported receiving very little practical support, such as looking after family members or grocery shopping, from family and friends. Instead, parents reported relying on paid professionals for practical support, with some parents stating that asking for help from family and friends felt like an imposition. Although 25 of the 34 families reported that “some” or “many” of their children’s needs were met, 16 families reported that “none” or “very few” of their needs related to caring for their child were being met while 10 reported that “some” of their children’s care needs were met. While the receipt of practical support was consistently low across the families who were interviewed, parents’ reports of the amount of emotional support they received was much more variable, with some reporting very low emotional support, others reporting moderate support, and others still reporting that they received a great deal of emotional support from their family and friends. In terms of parents’ satisfaction with the support they received, Brown et al. (2003) found that parents who were receiving the sort of support they wanted reported greater satisfaction with their supports and services (*r* = .56, *p* = .001). In a large sample (*n* = 923) of parents who had accessed services through family support agencies in the province of Alberta, McConnell et al. (2010) found that both financial hardship and parent stress mediated the relationship between socio-economic status and child difficulties. Furthermore, parent social support had a main effect on parent stress, ineffective parenting strategies, and on child difficulties, suggesting that interventions aimed at improving parent social support may have significant positive benefits for the parent-child relationship.

From its inception as the ecological model of human development, Bronfenbrenner's model has undergone a number of revisions and has evolved into its current form, known now as the bioecological model. In the bioecological model Bronfenbrenner and his colleagues (Bronfenbrenner, 2001; 2005; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 1998) built upon the original model, developing and expanding several key concepts, including that of *proximal processes*, giving more weight to the role that these take in shaping human development. Proximal processes are conceptualized as the primary mechanism by which human development occurs and as such, proximal processes are influential over time and throughout people's lives. Over time these proximal processes will vary as a function of the individual person, of environmental contexts, and of the historical time period in which development is taking place (Bronfenbrenner & Morris, 1998). The particular role of specific individual characteristics in promoting or hindering development was an important addition to the model. Bronfenbrenner and his colleagues (Bronfenbrenner 2001; Bronfenbrenner & Morris, 1998) identified three individual characteristics that are instrumental whenever the micro and macro systems interact: (a) dispositions, which initiate proximal processes and can sustain them over time; (b) bioecological resources, which are the abilities, experiences, knowledge, and skills of the individual; and (c) demand characteristics, which either facilitate or impede interactions with the environment. Within this framework, objects and symbols are as likely as people to serve as proximal processes in the individual's life. For instance, a parent’s playful interactions with his child would be considered a proximal process, as would the child’s independent exploration of her environment and her subsequent interaction with books, toys, and other objects. Consistent involvement in such proximal processes fosters a child’s knowledge and motivation. Conversely, inconsistent or negative interactions may impede a child’s development (Bronfenbrenner, 2001).

One of the key evolutions of the original model is the accordance of a more prominent role to *time* in human development (Bronfenbrenner & Morris, 1998). The influence of time is incorporated into the bioecological model at three different levels: the micro level, the meso level, and the macro level. Microtime is thought of as “continuity and discontinuity within ongoing episodes of proximal processes,” while mesotime is “the periodicity of these episodes across broader time intervals, such as days and weeks,” and macrotime is “the changing expectations and events in the larger society, both within and across generations, as they affect and are affected by, processes and outcomes of human development over the life course” (Bronfenbrenner & Morris, 1998, p. 995).

Bronfenbrenner (2001) put forth 10 guiding propositions of the bioecological model. Three of these are discussed in detail by Bronfenbrenner and Evans (2000) and by Bronfenbrenner and Morris (1998) and are relevant to the proposed project. *Proposition I* holds that in order for human development to be successful, individuals must engage in reciprocal interactions with their environment. These are the proximal processes discussed above, and in order for these processes to be effective in shaping development, they must occur regularly and over extended periods of time. *Proposition II* holds that the form, power, content, and direction of proximal processes all vary as a function of the person, the environment, developmental outcomes, and the social context over time. In this way, Bronfenbrenner suggests that the individual is both the producer of his or her development as well as the product of this development. *Proposition III* holds that in order to be effective, the reciprocal interactions discussed in *Proposition I* must become increasingly complex over time and should occur between individuals who share an “irrational” attachment to one another, that is, between a parent and a child. Taken together, Bronfenbrenner's original ecological model of human development and its more recent evolution, the bioecological model, serve as guides for the current study, in particular the research questions the study aims to address (see Chapter 3 for study goals and research questions).

Chapter 2: Review of the Literature

The following review of the literature will start by presenting the rationale for the use of a non-categorical approach, then the relationship between parenting and child functioning will be explored, followed by an examination of the role of supports and services in the well-being of children with NDD and their parents, and will conclude with a review of the literature on parents' perceived need for and access to services for their children with NDD. Gaps in the existing research will be identified, and the rationale for the present research will be presented.

Why a Non-Categorical Approach?

In line with current research and policy priorities that focus on improving the lives of all individuals with disabilities, regardless of specific condition aetiology (Ronen et al., 2011), the focus of the current investigation is on child well-being as a correlate of level of functioning, rather than diagnosis. As outlined above, a non-categorical approach was chosen as there is now a large theoretical and empirical knowledge base showing that there is more variability within than between diagnostic groups (e.g., Gannoni & Shute, 2010; Ronen & Rosenbaum, 2013; Simeonsson, Leonardi, Lollar, Bjorck-Akesson, Hollenweger, & Martinuzzi, 2003; Stein & Jessop, 1989) and that child function affects parenting more than diagnosis (Abbeduto et al., 2004; Azad, Blacher, & Marcoulides, 2013; Eisenhower, Baker, & Blacher, 2009; Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006; Lewis et al., 2006; Neece, Green, & Baker, 2012). Some researchers have argued the importance of taking a condition-specificity approach to developmental research, focusing on specific behavioural phenotypes and their direct sequela (e.g., Burack, 1990; Hodapp, 1997). This view holds that condition-specific behaviours have both direct and indirect effects, affecting the individual who has the disability and the family or environment that surrounds the individual (Hodapp, 1997). Support for this position comes primarily from studies examining children with Down syndrome and children with autism spectrum disorder (ASD; Abbeduto et al., 2004). For instance, researchers have found that some families of children with Down syndrome show a Down syndrome advantage, whereby parents of children with Down syndrome experience less stress and more positive interactions with their children than parents of children with other disabilities (e.g., Hodapp, 1997; Hodapp, Ly, Fidler, & Ricci, 2001; Hodapp, Ricci, Ly, & Fidler, 2003). One possible reason for such an advantage is that children with Down syndrome have been found to display fewer maladaptive behaviours than children with other diagnoses (e.g., Dykens, Hodapp, & Foucane, 2000; Ricci & Hodapp, 2003). Similarly, in both quantitative and qualitative investigations, children with ASD have been reported to display more problem behaviours, which may negatively impact parenting (e.g., Bromley, Hare, & Emmerson, 2004; Kasari & Sigman, 1997; Olsson & Hwang, 2001). Therefore, those investigators who suggest adopting a condition-specificity, or categorical, approach to studying childhood disability do so with the objective of drawing conclusions about developmental trajectories and ultimately, informing specific therapeutic interventions (Hodapp, 1997).

The opposing position is that of a non-categorical approach, which advocates for a shift in focus away from conditions or diseases and toward the impact (outcome) of conditions on the child (Perrin et al., 1993). There is often a misguided belief that medical diagnoses are the most objective descriptors of a condition. Yet, making a diagnosis requires clinical judgement, and even when a diagnosis is made based on biological markers, there is variability in how clinicians arrive at their decisions (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). Furthermore, relying on lists of diagnoses means that only the most prevalent disorders are included, at the exclusion of conditions with low prevalence rates, even though when aggregated, children with less common conditions make up a considerable percentage of the total number of children with chronic health conditions (Stein et al., 1993). A further difficulty with relying on diagnosis is that some conditions are more easily diagnosed than others; if the aetiology is unknown a child with marked behavioural symptoms may go undiagnosed for years despite acute difficulties (Stein et al., 1993). Returning to the notion that understanding the outcome of a condition is more practically relevant for the lives of children with disabilities and their families, examining just a diagnostic label is insufficient. There is large variability in the manifestation of conditions, including the frequent presence of comorbid conditions which may have more than just additive effects on the individual's functioning (Stein et al., 1993). Therefore, Stein and her colleagues (Stein et al., 1993) proposed a framework based on the consequences of conditions rather than on diagnosis. Such a framework allows for the level of severity to be adjusted based on individual characteristics or on the specific outcomes related to a condition such as function or the burden on individuals, families, or society as a result of the condition.

Using data from two large studies, one drawing on an institution sample and the other a population-based study, Stein and Jessop (1989) used diagnostic groupings as their independent variable and psychological, social, and educational measures as their dependent variables. Their results indicated no significant differences between diagnostic groups on any of the measures except for the family's interaction with the healthcare system, a result that can be accounted for by the different medical needs of the participants. Overall, Stein and Jessop concluded that there was more variability within than between the diagnostic groups and diagnosis was therefore not helpful in elucidating the psychosocial impact of chronic health conditions. More recently, increasing numbers of researchers are adopting a non-categorical approach, and arriving at similar conclusions. For instance, Lewis et al. (2006) compared the psychological well-being of mothers of children with fragile X syndrome and comorbid ASD ($n = 9$) and mothers of children with fragile X syndrome only ($n = 19$). A control group of mothers of children with Down syndrome was included as well ($n = 19$). A significant difference was found between diagnostic groups on a single subscale of the Family Environment Scale; parents of children with fragile X syndrome and comorbid ASD reported more conflict than parents of children with Down syndrome, and parents of children with fragile X syndrome only reported marginally more conflict than parents of children with Down syndrome. There was also a significant effect for reciprocal closeness, with mothers of children with fragile X syndrome and comorbid ASD reporting lower levels of reciprocal closeness than either of the two other groups. However, in terms of the impact of diagnosis on parental psychosocial functioning, the results showed no significant differences between groups on the Center for Epidemiologic Studies Depression Scale (CES-D), a measure of depressive symptomatology, nor any significant differences in life satisfaction or parental coping style. Given the literature cited above showing that children with ASD display characteristic problem behaviours, Lewis et al. further examined whether severity of ASD behaviour was related to parent well-being. In order to control for possible reporter confounds, the investigators compared fathers' ratings of their children's ASD behaviours with mothers' self-reported well-being. They found that ASD behaviours were not predictive of maternal psychological well-being. The authors highlight the importance of controlling for reporter confounds and suggest that many studies may be conflating the relationship between diagnosis-specific behaviour and maternal well-being by having mothers report on both constructs.

Rodrigues and Patterson (2007) examined the impact of the severity of children's chronic health conditions on family functioning. Mothers and fathers of two cohorts of children (*n* = 160 families of infants between six and 24 months of age; *n* = 102 families of children between eight and 10 years of age) with chronic health conditions (defined as a condition that has a biological basis, has lasted at least one year, and produces long-term consequences) completed the Family Assessment Measure and the Functional Status Questionnaire. The results indicated that overall these samples showed similar levels of family functioning when compared with normative samples. Furthermore, in line with the hypothesis, the results showed that greater functional severity of the child's condition was associated with poorer family functioning, according to both mothers and fathers. The only difference between mothers and fathers was found for role performance, with mothers reporting lower role performance than fathers in this study.

In a qualitative study that involved focus groups and individual interviews with pre-adolescent and young adults with chronic illnesses (*n* = 14) and their parents (*n* = 18; *n* = 16 mothers, *n* = 2 fathers), Gannoni and Shute (2010) gathered information about the lived experiences of these families in relation to their adaptation to the youth's chronic condition. A cross-diagnostic approach was taken, with youth with type 1 diabetes, cancer, and chronic renal failure included in the sample. The authors report that this non-categorical methodology was supported by their findings as there were many common concerns and issues raised across the three groups. For instance, of the themes to emerge, many touched on the positive experiences associated with having a chronic condition. Parents reported increased confidence in their parenting capacity and pride in their children's increased responsibility as well as positive attitudes about their children's emotional maturity and behaviour. The mothers and fathers in this study also found ways to cope with the new situation as a family, sometimes taking on different or complementary roles. Parents and children across the diagnostic groups reported similar emotional reactions to the child's condition, including sadness, confusion, shock, fear, and nervousness. It was also reported that the child's condition had a negative impact on the family's participation in activities and led to increased financial concerns. Parents across the groups experienced issues with communication, both with professionals and between spouses. Although Gannoni and Shute found some differences between groups, these differences were primarily restricted to treatment-related concerns for the group of families whose children had a cancer diagnosis. The authors emphasize the many common issues that were raised across the three groups, and argue that there is much to be gained when shared perspectives are examined together.

Similar results were obtained in a meta-analysis of 38 studies examining the correlates of psychosocial adjustment for children with physical disorders (Lavigne & Faier-Routman, 1993). These authors found that although diagnosis, child characteristics, and family and parent variables were all significantly related to child psychosocial adjustment, diagnosis was a much weaker predictor than the family and parent variables such as life stress and coping. Therefore, Lavigne and Faier-Routman (1993) argue that it is the psychosocial variables that are independent of disability status that are most important when examining outcomes for children with physical disabilities. In line with these findings, more recently Knafl, Knafl, Gallo, & Angst (2007) focused on common psychosocial challenges for families of children with genetic conditions, rather than on the biological aspects of disease. The results of their mixed-methods study, which included semi-structured interviews and standardized questionnaires, revealed common patterns of family functioning that characterize several genetic conditions, and it was these functional variables which predicted child and family outcomes.

When taken together, it appears that condition-specific analyses can have a place in research and clinical intervention when the aim is remediation of specific behavioural pathways in children's development (Hodapp, 1997). However, condition-specificity has its limitations, and there are circumstances in which a non-categorical approach may be preferable. At a practice level, categorical approaches will miss the large numbers of children who have rare genetic conditions or whose diagnoses are unclear. At a policy level, it must be recognized that policies are not usually focused on specific conditions (Arim et al., 2015). Moreover, when the aim is to uncover correlates of psychosocial functioning for families, the research evidence indicates the need for a non-categorical approach whereby commonalities across disabilities can be examined in order to provide meaningful insight and change for families.

Parenting and Child Functioning

Studies investigating families who are at risk for poor developmental outcomes have shown that when parents are under high levels of stress they show less effective parenting skills (Ostberg, 1998; Secco et al., 2006). Parent mental and physical health has also been found to mediate the relationship between high family stress and child mental health (Quinn, Briggs, Miller, & Orellana, 2014). In addition, families supporting a child with NDD have been found to be significantly more economically disadvantaged when compared with families supporting a child without NDD (Emerson, 2003; Emerson, Graham, McCulloch, Blacher, Hatton, & Llewellyn, 2009; Emerson, Madden, Graham, Llewellyn, Hatton, & Robertson, 2011; Parish, Mailick Seltzer, Greenberg, & Floyd, 2004), and socio-economic status has been found to correlate significantly with child outcomes (e.g., Jackson, Choi, & Bentler, 2009; Robins, Dunlap, & Plienis, 1991; Saridjan et al., 2010; Spence, Najman, Bor, O'Callaghan, & Williams, 2002; Venetsanou & Kambas, 2010).

Researchers have shown that the quality of parent-child interactions is central to the development of children (e.g., Hauser-Cram et al., 2001; Martin & Cole, 1993; Minnes, 1998) and that positive parenting strategies in early childhood can help to mitigate negative developmental outcomes for children at risk of developmental delay (Fenning & Baker, 2012). Yet, parents of children with NDD may be more likely to use ineffective parenting strategies. For instance, drawing on the Canadian population-based National Longitudinal Survey of Children and Youth, Garner and her colleagues (Garner et al., 2013) found that parents (approximately 98% of whom were biological mothers) of children who had both NDD and behaviour problems reported having fewer positive interactions with their children than parents whose children were typically developing. Parents of children with NDD often experience atypical interactions with their children that are due in part to child characteristics that are different from typically developing children. For instance, children with NDD often display a greater number of behaviour problems than typically developing children. Problem behaviours can include aggression, destructiveness, defiance, hyperactivity, sleep disturbances, and anxiety (Feldman, Hancock, Rielly, Minnes, & Cairns, 2000; Jewell, Jordan, Hupp, & Everett, 2009; Keller & Fox, 2009). These problem behaviours can have negative effects on parents due to the stress the behaviours cause and due to the added time management that the behaviours often require (Plant & Sanders, 2007). The presence of behaviour problems in children with NDD has been linked to elevated stress in their parents (e.g., Bromley, Hare, Davison, & Emerson, 2004; Brossard-Racine et al., 2012; Hassal et al., 2005; Hauser-Cram et al., 2001; Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2012; Pisula, 2007) as well as negative feelings about parenting (Sikora et al., 2013). Furthermore, the relationship between child behaviour problems and parent stress has been found to persist across childhood (Azad et al., 2013; Neece et al., 2012). In a longitudinal study of 219 mothers of children with (n = 94) and without (n = 125) NDD (diagnoses included Down syndrome, autism spectrum disorder (ASD), and cerebral palsy) who were enrolled in the Collaborative Family Study, Azad et al. (2013) examined predictors of maternal stress during early (ages three to five) and middle (ages six to nine) childhood. These researchers found that child behaviour problems and child social skills were both predictive of maternal stress in early childhood and this relationship persisted into middle childhood, irrespective of child disability status. Nevertheless, in a related study of participants from the Collaborative Family Study, Eisenhower, Blacher, and Baker (2013) found that although child behaviour problems impacted the health and well-being of mothers of children with and without disabilities, the impact of behaviour problems on mothers' well-being was stronger when their children had NDD as opposed to when their children were typically developing.

Adaptive behaviour, that is, the collection of conceptual, social, and practical skills that allow individuals to function in their daily lives (American Association on Mental Retardation, 2002), is often limited in children with NDD. Adaptive behaviour is assessed within the individual's environmental context, taking into account the age of the individual and cultural and social expectations (Sparrow, Cicchetti, & Balla 2005). Several areas of functioning fall under the umbrella of adaptive behaviour, including activities of daily living, as well as communication and socialization skills. Children who struggle with the day to day activities cited above require support from a parent or caregiver to accomplish these tasks. For children with disabilities, this struggle is common and is often present across areas of daily living and across the lifespan (Bailey, Raspa, Holiday, Bishop, & Olmsted, 2009; Haveman, van Berkum, Reijnders, & Heller, 1997; Patel, Greydanus, Calles, & Pratt, 2010; Stewart, 2009). The added strain of performing more daily living tasks for their children with NDD than parents of typically developing children can lead to elevated stress in parents of children with NDD (Beckman, 1991; Majnemer et al., 2012; Plant & Sanders, 2007). Plant and Sanders (2007) examined care-giving stress in mothers of preschool-aged children (<6 years of age) with developmental disabilities living in South-East Queensland, Australia. Controlling for demographic factors such as child gender, child age, marital status, family income, and maternal education, these authors found that stress in mothers was related to care-giving tasks for their children, such as helping and supervising at meal times, cleaning up after their child, bedtime preparation, and helping and supervising toileting, with increased demands correlating with higher stress in mothers. For instance, difficulty of caregiving tasks was reported to be significantly higher for mothers who reported high stress compared to those who reported low stress (M = 32.35 and M = 20.04, respectively, p < .01). Similarly, difficulty of child behaviour during care giving tasks was also significantly different between the high and low stress groups (M = 22.18 and M = 30.49, respectively, p < .01). While Plant and Sanders attempted to obtain responses from both mothers and fathers, significantly more mothers (n = 105) than fathers (n = 34) completed all measures, thus principal analyses were conducted using only maternal responses. The majority of children were male (70%) and had either a mild (45%) or moderate (30%) level of disability, with only a small percentage of children reported as having a severe level of disability (8%), determined via parent reports on the Vineland Adaptive Behavior Scales – Survey Interview Form. Child diagnoses were diverse and included ASD, Down syndrome, chromosomal abnormality other than Down syndrome, and cerebral palsy. This study examined only one time point and did not control for either current or past service use, which limits the generalizability of the findings.

Haveman and colleagues (Haveman et al., 1997) conducted a national large-scale cross-sectional study of primary caregivers of individuals with intellectual disabilities (ID) in the Netherlands. Their sample included biological, adoptive, and foster parents and comprised one caregiver per household who self-identified as the primary caregiver (85% mothers and 15% fathers). Haveman et al.(1997) found differences in daily living skills between individuals with mild or moderate ID and individuals with severe ID (n = 2,573). For instance, these researchers report that among children in the youngest age group (birth to nine years of age), those with mild or moderate ID required less help than children with severe ID on the following tasks: eating (28% of children with mild or moderate ID versus 78% of children with severe ID), toileting (34% versus 80%), and dressing (55% versus 92%). These group differences weakened in the older age groups, but remained persistent nonetheless. This study is limited by its use of cross-sectional data, yet it nonetheless provides useful information regarding the additional demands that primary caregivers of children with NDD face over time. Further, in a study of parents (64% mothers) of children with

ID (*n* = 112) with (*n* = 46) and without (*n* = 66) severe behavioural difficulties, children with chronic illness (*n* = 73) with (*n* = 28) and without (*n* = 46) severe behavioural difficulties, and children with diagnosed behavioural problems (*n* = 46), Floyd and Gallagher (1997) found that children with ID were reported to have the lowest community self-sufficiency scores of the three groups (*F*(4, 192) = 7.48, *p* < .001) while children with behaviour problems were reported to have the lowest personal social responsibility scores (*F*(4, 195) = 9.42, *p* < .001). Floyd and Gallagher examined potentially confounding factors, including marital status, socioeconomic status, and child gender, but found no significant differences. Significant differences were found between groups on the variables of child and maternal age, with children with ID and their mothers being significantly older than the children and mothers in the other two groups because the ID sample was recruited five years earlier in a previous wave of data collection. Significant differences were also found between the chronic illness group and the other two groups on the variable of maternal education, and between the ID group and the other two groups on the variable of cognitive functioning. In each case of a significant difference these variables were controlled for in the final analyses.

Hauser-Cram and her colleagues (Hauser-Cram et al., 2001) conducted a comprehensive 10-year prospective longitudinal study of children with developmental disabilities (*n* = 183) who attended early intervention programs in the North Eastern United States. Children had diagnoses of Down syndrome, motor impairment, or developmental delay of unknown etiology. Children with Down syndrome were no more than 12 months old and children with either motor impairment or developmental delay were no more than 24 months old when they entered the study. All children were assessed at study entry (when they began early intervention programming), at three years of age (when they exited early intervention), and at three additional time points between age three and age 10. For both the group of children with motor impairment and the group with developmental delay, only those children who continued to meet criteria for these diagnoses at age three were included in the longitudinal study. Some demographic differences were observed between the three groups at entry into the study. There were slightly more children with motor impairment (39.3%)

than with either Down syndrome (32.8%) or developmental delay (27.9%) and there were slightly more males (57.4%) than females (42.6%). The majority of families were of European American descent (89.1%), had at least 14 years of education, and were married. The authors note that while this sample was chosen to be representative of the American population attending early intervention programs when the study started in 1985, at the time of publication for the longitudinal results, it was no longer an accurate reflection of families of children with developmental disabilities attending early intervention. While this does not negate the findings of the study it is nonetheless important to consider them within this context. Hauser-Cram et al. (2001) found that several child characteristics were predictive of later adaptive functioning. Children with motor impairment had less growth in their daily living skills (ß = -.079, $p < .05$) compared to children with either Down syndrome or other developmental delays of unknown aetiology, over a seven year period. In addition, children who had higher mastery motivation, that is, a higher drive to independently complete challenging tasks, at age three showed greater growth in the development of daily living skills over time (ß = .030, $p < .01$). Moreover, children's mental age was a partial mediator of adaptive behaviour in both the communication and daily living domains of the adaptive behaviour assessment (the Vineland Adaptive Behavior Scales). Patterns of family interaction also predicted later child adaptive behaviour. For each participating child, both mother and father completed the Parenting Stress Index (PSI). In addition, the Nursing Child Assessment Teaching Scale (an observational rating scale that assesses teaching interactions) was used to record mother-child interactions for each child. Mothers with higher mother-child interaction scores and families with more positively rated family relations had children who experienced greater positive change in their socialization skills. Furthermore, mothers of three-year-old children with developmental disabilities who had higher adaptive behaviour skills (regardless of their diagnosis) reported less child-related stress than mothers of children who had poorer adaptive behaviour (ß = -.771, $p < .001$). What these results reveal is that children with various NDD do experience difficulties with adaptive behaviour, although there are differences between groups and differences between children based on individual characteristics such as motivation and cognitive functioning. In line with Bronfenbrenner’s bioecological model, the complex nature of parent-child-environment interactions is also elucidated by Hauser-Cram et al.’s findings, suggesting that the developmental trajectories of children with NDD cannot be considered in isolation and must include an investigation of the various intrinsic and environmental factors that affect them.

Parental adaptation to a child's disability is a complex and lifelong process (Hauser-Cram et al., 2001; Poehlmann et al., 2005), one that can change over time as a result of, for example, changes in the parent-child system. Child and parent needs are too often considered in isolation, ignoring the relationship that exists between them. When considering parent stress and its relationship with child characteristics, a transactional model of development (Sameroff & Chandler, 1975; Sameroff & Mackenzie, 2003) that accounts for the nested micro-, meso-, exo-, and macrosystems (Bronfenbrenner, 1977) in children’s lives can help to guide our understanding of the dynamic processes involved. For instance, Friedrich, Wilturner, and Cohen (1985) examined stress in three different samples of mothers of children with intellectual disability (ID): mothers of children with ID with no motoric or sensory handicaps ($n = 49$), mothers of children with ID with comorbid cerebral palsy ($n = 41$), and mothers of children with Down syndrome ($n = 30$). There was a significant contribution of medical involvement to overall family problems, with mothers of children with higher scores on a measure of medical involvement (problems with speech and language, eating, sleeping, toileting, and physical and motor areas) reporting more stress than mothers who scored lower on this measure of medical involvement ($F(2, 137) = 23.4$, $p < .0001$, $R^2 = .17$). Results of regression analysis revealed that medical involvement accounted for 2% of the variance of parent and family problems, behaviour problems (conceptualized as the sum of the child's internalizing and externalizing behaviours) accounted for 10% of the variance, and maternal coping resources accounting for a final 36% of the variance in parent and family problems. The authors hypothesize that the relationship between the variables is likely bidirectional, with parent problems contributing to child behaviour problems and vice versa (Friedrich et al., 1985).

More recently, Neece et al. (2012) followed a sample of 237 families of children with (*n* = 93) and without (*n* = 144) developmental delays from the ages of three to nine years. Recognizing the fact that the majority of studies capture only (or mostly) mother's reports, Neece et al. sought out to examine both mothers' and fathers' experiences of parenting and parent stress. Using growth modelling procedures, they found support for a transactional relationship between child behaviour problems and parent stress over time for both mothers and fathers, irrespective of child disability status. Child behaviour problems and parent stress were found to co-vary, suggesting that child behaviour problems are both an antecedent and a consequence of parent stress, and vice versa.

Supports and Services

Following Bronfenbrenner's (1979) model, it is likely that the relationship between child functioning and parent well-being is influenced by environmental factors. The relationship may be an indirect one, factors such as social support (e.g., Benson, 2012; Miodrag & Sladeczek, 2009), coping resources (e.g., Beresford, 1996; Lopes, Clifford, Minnes, & Ouellette-Kuntz, 2008; Woodman & Hauser-Cram, 2013), family-centred service provision (e.g., Dunst, 2000; Dunst, Trivette, & Hamby, 2007; Guralnick, 2005), or positive interactions with service providers like the school system (Burke & Hodapp, 2014) may act to mediate or moderate the relationship between the two constructs.[3] For example, Simons, Lorenz, Wu, and Conger (1993) examined the roles of social network support and marital support in mediating and moderating the effects of economic pressure and depression on the quality of parenting behaviour. Simons and his colleagues (Simons et al., 1993) tested a model of the determinants of parenting using a sample of two-parent families (*n* = 451) who had a child in Grade 7 and at least one other child who was within a four year age range of the seventh grader. Information on the parents' economic pressures, social support

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[3] In a mediated relationship between two factors, the independent variable acts on the dependent variable via the mediator (Shadish & Sweeney, 1991) and, more specifically, the mediator clarifies the way in which the independent variable is related to the dependent variable (Baron & Kenny, 1986). In order for a mediator to exist, there must first be a significant relationship between the independent and dependent variables (Holmbeck, 1997). Moderators, on the other hand, are introduced when the relationship between the independent and dependent variables is either weaker than expected, or is inconsistent (Baron & Kenny, 1986). The addition of a moderator to an equation strengthens the relationship between the predictor variable and the criterion variable so that the predictor's association with the criterion varies as a function of the level or value of the moderator (Holmbeck, 1997).

networks, spousal support, depression, and supportive parenting was collected through interviews, observations, and parent-report measures completed with both parents. These researchers found main effects of both depression and spouse support on supportive parenting. In addition, several indirect effects were also reported. In line with the guiding hypotheses, spouse support was found to have an indirect effect on supportive parenting behaviour through depression; depression mediated the relationship between spouse support and parenting behaviour for both mothers and fathers. Furthermore, both spousal support and depression mediated the relationship between economic pressure and supportive parenting behaviour for mothers and fathers. For mothers only, depression also mediated the relationship between social network support and supportive parenting. Simons et al. (1993) also tested for a possible buffering effect of spouse support. First, parents were divided into two groups: those with high spouse support (above the median) and those with low spouse support (below the median). Subsequently, the investigators examined the relationships between economic pressure, social network support, depression, and supportive parenting at each of these levels of spouse support (either high or low). The results suggest that for mothers, spouse support moderated the effect of economic pressures on supportive parenting by reducing the relationship between depression and supportive parenting. There was no moderating effect of spouse support for fathers. In order to understand better the psychological well-being of fathers of children with NDD, Hartley, Seltzer, Head, & Abbeduto (2012) examined fathers of adolescent or young adult children with Down syndrome (n = 59), fragile X syndrome (n = 46), or ASD (n = 135). Paternal and maternal depressive symptoms were assessed using the Center for Epidemiologic Studies Depression Scale (CES-D) while fathers' psychological well-being was further investigated through the Pessimism subscale from the Questionnaire on Resources and Stress (QRS-F) and the Multidimensional Coping Inventory. Hartley et al. (2012) found no difference in fathers' use of emotion-focused or problem-focused coping resources between the diagnostic groups. Across diagnostic groups, Hartley et al. also found that paternal depressive symptoms were partially related to maternal depressive symptoms, while fathers of adolescents and young adults with ASD were found to have significantly higher levels of pessimism compared to fathers of adolescents and young adults with Down syndrome.

The well-being of children with NDD is therefore likely to be both directly and indirectly affected by environmental variables such as social and formal support, by personal factors such as coping resources (WHO, 2001), and also by the children's interactions with their parents, whose parenting is either supported or hindered by the supports and services the family receives. With regards to the impact of supports and services on families of children with NDD who attend early intervention programs, Bailey and colleagues (Bailey et al., 1998) have identified three key themes. First, since families differ in resources, priorities, concerns, and culture, an individualized approach is needed. For instance, some families may need or desire services that go beyond promoting child development (e.g., support groups for parents). Second, a partnership between families and service providers is needed to ensure that families are active in both planning and implementing services. Finally, the third theme is that of families as ultimate decision makers and long-term caregivers of their children. Given this, families must be enabled to become competent advocates for their children (e.g., Bailey et al., 1998; Guralnick, 2005, 2008), both early on and throughout their children's development.

Social support and parent well-being. As described in the introduction, well-being is conceptualized as an individual’s satisfaction with his or her life and this appraisal is based on both objective and subjective factors (McDowell, 2010). In 1985, Cohen and Willis conducted a review of the literature on the association between social support and well-being. Their aim was to explore whether the positive relationship that was repeatedly reported between social support and well-being was due to a main effect of social support (a “main-effect model”) through a supportive social network, or to a protecting or buffering effect of social support (a “buffering model”) whereby social support promotes well-being by bolstering individual resources and responses to stress, for instance, coping. Cohen and Willis (1985) concluded that both models were supported, but that they each represented different processes through which social support is beneficial. For instance, the main-effect model was supported by studies that examined the amount of support that individuals received from their social networks (e.g., Andrews, Tennant, Hewson, & Vaillant, 1978; Aneshensel, & Stone, 1982; Bell, LeRoy, & Stephenson, 1982; Cleary & Mechanic, 1983; Frydman, 1981; Gore, 1978; Lin, Simeone, Ensel, & Kuo, 1979; Miller & Ingham, 1979; Schaefer, Coyne, & Lazarus, 1981; Williams, Ware, & Donald, 1981). On the other hand, the buffering model was supported through studies that investigated the availability of individuals' perceived interpersonal resources in response to stressful events (e.g., Cohen & Hoberman, 1983; Frydman, 1981; Henderson, 1981; Henderson, Byrne, Duncan-Jones, Scott, & Adcock, 1980; Miller & Ingham, 1979; Wilcox, 1981).

Stevens (1988) examined the relationship between parenting behaviour and social support in a sample of low-income mothers (*n* = 198) who had infant children between 13 and 30 months of age. In order to obtain a representative sample and to ensure that there was an even distribution of both socially isolated and well-integrated families Stevens recruited families by going door-to-door in over 40 metropolitan neighbourhoods known to have high numbers of black and/or white low socioeconomic status families. Social support was defined as help-seeking behaviour from either family or friends. Stevens found that for black teenage mothers (*n* = 74), parenting skill was predicted by the mothers’ willingness to report parenting problems (accounting for 19% of the variance) and to seek help from extended family members (accounting for 6% of the variance). However, for black adult mothers (*n* = 62) only locus of control was significant. For this group, only maternal locus of control was a significant predictor of parenting skill (accounting for 21% of the variance). For the group of white adult mothers (*n* = 62), parenting skill was predicted by the mothers’ locus of control (accounting for 11% of the variance), seeking help from extended family members (accounting for 8% of the variance), and seeking help from professionals (accounting for 9% of the variance). This study examined a specific population in one particular American city, making generalization of the results to other populations highly problematic. However, while this is but one study, the results do nonetheless suggest that social support can significantly impact individuals' well-being and also their parenting behaviour.

There is a substantial body of research showing that social support can affect the well-being of parents of children with NDD in particular (Ammerman, et al., 1994; Antshel & Joseph, 2006; Benson, 2012; Boyd, 2002; Dunst et al., 1986; Dyson, 1997; Ebert et al., 1989; Floyd & Gallagher, 1997; Hassall et al., 2005; Lovell, Moss, & Wetherell, 2012; Miodrag & Sladeczek, 2009; Nachshen & Minnes, 2005; Poehlmann et al., 2005; Weiss, 2002). In their study of mothers of children with either ASD or Down syndrome ($n = 70$), Miodrag and Sladeczek (2009) found that in terms of support, only informal social support, and not formal support, was predictive of mothers' depressive symptoms, accounting for 9.1% of the variance. However, these researchers did not differentiate between those services the families were currently receiving and those they had accessed in the past, making definite conclusions about these results difficult. Nevertheless, other researchers have found similar results, thereby bolstering Miodrag and Sladeczek’s findings. For instance, in his review of the literature on the relationship between stress and support in mothers of children with ASD, Boyd (2002) found that informal social support, particularly in the form of spousal support, was more effective at protecting against stress than formal support. More recently, Lovell and his colleagues (Lovell et al., 2012) found that social support mediated the effects of stress (assessed via cortisol levels) and parent psychological and physical health for a sample of parents (87% mothers) of children with ASD or attention deficit hyperactivity disorder.

Antshel and Joseph (2006) compared mothers of children between the ages of 8 and 11 years who had a reading disorder ($n = 31$), nonverbal learning disorder ($n = 21$), or were typically developing and were matched on age, gender, and intellectual functioning ($n = 23$). There were no statistically significant differences between the groups in terms of gender, age, grade, Full Scale IQ, the percentage of ethnic minority participants, maternal age, or the mean number of children in the home. For mothers of children with nonverbal learning disorder the best predictors of maternal distress were child characteristics, including child intellectual functioning ($F(1, 19) = 15.94$, $p < .001$). For mothers of children with reading disorder, characteristics of the mother most predicted maternal distress, including the mother's age, level of reported psychiatric symptoms, and her level of social support as assessed by scores on the Social Supports Questionnaire ($F(1, 29) = 11.23$, $p < .001$). Antshel and Josheph's sample size was small and was recruited from a single outpatient treatment centre for individuals with learning disabilities (typical controls were recruited from four local schools), limiting the generalizability of the findings. What is more, the sample was further restricted in that it only included mothers, children of a restricted age range, and a greater number of boys than girls. Furthermore, Antshel and Josheph did not control for (or examine) formal supports and services accessed by the family. Thus, these results must be interpreted with caution and within the context of the particular research environment.

Examining three types of informal social support (availability of social support, receipt of functional social support in the form of help provided by friends or family, and marital satisfaction and harmony) in mothers of children between the ages of two and seven with ASD ($n = 40$), intellectual disability ($n = 40$), and typically developing controls ($n = 40$), Weiss (2002) found that the groups differed significantly in terms of their perceived levels of available social support ($F = 10.58$, $p < .002$); perceived emotional support and esteem-boosting friendship were rated as most available by mothers of typically developing children, as somewhat available by mothers of children with intellectual disability, and less available by mothers of children with ASD. Perceived levels of available social support was also found to predict maternal stress, with mothers who reported a high degree of social support reporting lower levels of depression ($r = .33$). However, the sample was homogeneous with the majority of respondents being married, Caucasian, and of average socioeconomic status. In addition, participants were recruited through only two specialized schools and one conference, thus generalizability of the findings to different populations is made difficult.

Social support has also been found to affect parenting directly. In a study of psychiatrically hospitalized children and adolescents with developmental disabilities ($n = 138$) and their mothers, Ammerman et al. (1994) found that mothers were more likely to use severe disciplinary measures with their children if the mothers reported low levels of social support, defined as the degree to which social relationships were perceived to meet the mothers' needs (ß = -.16, *t*(103) = -2.01, *p* < .05) and high anger reactivity (ß = .26, *t*(103) = 3.22, *p* < .01). Aiming to uncover sources of resilience and stress in families with adolescents and young adults with NDD, Poehlman and her colleagues (Poehlman et al., 2005) conducted a series of open-ended interviews with mothers of children with either fragile X syndrome or Down syndrome (*n* = 21). They found that the most important theme to emerge in mothers' narratives was the presence or lack of social support, in the form of help with their child, from people in their environments. When taken together, the studies presented in this section all support the notion that social support impacts the well-being of parents.

Child well-being, participation, and the environment. The impact of social support on child well-being has also been explored. For example, Collins et al. (1993) examined the relationship between social support and both infant and maternal well-being in a sample of primarily low-income mothers (*n* = 129) attending a public prenatal clinic. Collins et al. (1993) found that mothers who reported the quality of the support they received as high also reported lower depression during pregnancy (*r* = -.24). In addition, these researchers found that mothers who reported being satisfied with the support they received from the baby's father also experienced less prenatal depression (*r* = -.32). Furthermore, mothers who reported more satisfaction overall with the support they received and who reported more support had infants with higher Apgar scores (ß = .29 and ß = .19, respectively). When these associations were broken down, it was found that higher Apgar scores were primarily associated with the receipt of task and informational support. Mothers who had more network support (e.g., family members and friends living close by and living with the child's father) were found to have infants with higher birth weights (ß = .20). When the interaction between stressful life events and overall satisfaction with social support (with overall satisfaction scores obtained by summing across types of social support) was examined, Collins et al. (1993) found that when stressful life events were reported to be low, there was no relationship between the quality of social support and infant birth weight. However, when stressful life events were high, better social support was predictive of higher infant birth weight (ß = .26).

Some studies have examined the relationship between parent social support and child adjustment. For instance, Barakat and Linney (1992) examined mothers' reports of social support in relation to adjustment and well-being in their children with myelomeningocele (the most severe form of spina bifida) without intellectual disability (n = 29) or children without physical handicaps or chronic illness (n = 28). Social support was assessed via the Modified Arizona Social Support Interview Schedule (ASSIS), which is administered with mothers in the form of a structured interview. Three specific areas of the ASSIS were used by Barakat and Linney: mothers' perceived available support network, the proportion of family members in the available network, and mothers' overall satisfaction with support. The results suggest that children whose mothers reported higher social support displayed fewer externalizing behaviour problems (R^2 change = .37, F = 5.84, $p <$ .01). Dunst and his colleagues (Dunst et al., 1986) explored the impact of social support for mothers (n = 96) and fathers (n = 41) of children with intellectual disability (n = 38), with physical disabilities (n = 29), or who were at risk for developmental disabilities (n = 29). Controlling for SES, child age and sex, and child developmental quotient and diagnosis, Dunst et al. (1986) found that parents' satisfaction with and the number of supports they received were significantly related to all of the study outcomes. In addition, parents who had larger social support networks reported that their children had more opportunities to participate in activities both within and outside the home (I = .04, $F(1, 122) = 9.45$, $p < .05$). Social support also mediated parents' perceptions of their children's behaviour, with parents who had older children and who reported more support also reporting that their children displayed fewer behaviour problems (I = .03, $F(1, 122) = 4.79$, $p < .01$). Finally, parents who reported better social support also reported more developmental gains for their children, especially when their children were younger (I = .04, $F(1, 124) = 9.60$, $p < .01$). On the other hand, in a study comparing mothers of children with chronic illness (n = 91) and mothers of children without chronic illness (n = 97), Perrin and her colleagues (Perrin et al., 1993) found that mothers' social support, assessed by mothers' perceptions of the size of their social network, did not affect child adjustment. Thus, the effect of familial supports and services on child well-being remains unclear.

Few studies have explored the relationship between social support and child well-being in children with NDD, and those that have show mixed results. Examining a sample of children and adolescents with spina bifida ($n = 72$) and a sample of age-matched controls ($n = 72$), Appleton and his colleagues (Appleton et al., 1997) used child self-report measures to assess the relationship between social support and child and adolescent well-being. The group of children and adolescents with spina bifida was significantly different from the comparison group, reporting greater depressive symptoms, lower global self-worth, lower energy, and more suicidal ideation. In addition, the authors reported that for all participants there was a significant direct effect of perceived parental support on depressed mood (Adjusted $R^2 = .50$, ß = .34, $p < .01$), and a mediating effect of global self-worth on the effect of physical appearance on depressed mood (Adjusted $R^2 = .61$, ß = .48, $p < .01$). Bier and colleagues (Bier et al., 2005) examined health-related quality of life in a sample of children and young adults with myelomeningocele ($n = 34$). The participants had a mean IQ of 85 (SD 18, range 36 to 111) and were assessed on their level of functional independence, determined by their self-care, mobility, and social cognition skills. Whenever possible, the individuals with myelomeningocele completed the measures themselves. Where this was not possible, parents answered for their children. Bier et al. (2005) found that social support, as measured by the Support Function Scale, which evaluates the family’s need for social supports, was not related to the children's quality of life. However, children's functional independence, assessed by an overall score obtained from a measure of functioning that examined self-care, sphincter control, transfers, locomotion, communication, and social cognition, was related to quality of life ($R = 0.744$, $R^2 = 0.553$, $p = 0.001$), suggesting that child functioning may play an important role in children's self-perceptions of their well-being. Studying children with learning disabilities ($n = 56$), Rothman and Cosden (1995) found that children's perceptions of the social support they received from both their parents and their classmates were significantly related to more positive feelings about their disability, more global self-worth, and higher intellectual, behavioural, and social competence ($F(4, 51) = 4.21$, $R^2 = .25$, $p < .01$).

Since the publication of the ICF and ICF-CY, a growing body of research has emerged that suggests that participation may be an acceptable indicator of well-being in children (Almqvist, 2006; Badia, Orgaz, Verdugo, Ullán, & Martínez, 2013; Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012; Imms, 2008; King et al., 2006; Law, 2002; Renwick & Fudge Schormans, 2004; WHO, 2007). Dahan-Oliel et al. (2012) conducted a systematic review of the literature examining the relationship between leisure participation of children and youth with NDD and quality of life (QoL). For their analyses these authors retained 19 studies that encompassed quantitative, qualitative, and mixed methods methodologies. Seven themes were identified to account for the effect of participation on QoL. Overall, leisure participation was found to have a positive impact on physical well-being, self-perception and self-esteem, emotional well-being, social well-being, and cognition. In addition, control over participation, for instance being able to choose in which activities they participated, had a positive impact on children’s QoL. Some negative aspects of leisure participation were also identified. For instance, some studies reported that children felt less competent than their peers during informal leisure activities such as recess, while other studies reported that children were less involved when equipment or environments were not modified to be accessible or when there were financial constraints. These environmental barriers to participation likely mediated the relationship between children’s leisure participation and their well-being (Dahan-Oliel et al., 2012), a finding that other recent studies have also reported (e.g., Anaby et al., 2014). Together with the ICF guidelines, these findings suggest that environmental modifications are important for facilitating participation, and that increased participation has a positive impact on the well-being of children with NDD.

Almqvist (2006) conducted a comprehensive investigation of well-being in a sample of preschool-aged children with and without developmental delay who were between the ages of 12 and 45 months ($n = 1035$). Health and well-being were operationalized in this study as child engagement, which was defined as the amount of time the child spends actively participating in her environment at different levels of competence. Each child's parent and preschool teacher completed questionnaires regarding the child's participation and engagement. The results suggested that participation and engagement are highly correlated in young children and that children's interaction skills and the availability of activities are strong predictors of high-level engagement, regardless of the children's level of functioning. A strength of this study is the use of both parent- and teacher-report data, which allows for an examination of objective indicators of participation across multiple environments.

Compared to children without disabilities, children with disabilities have been found to participate less in both structured and unstructured activities at school (Anaby & Law, 2013; Eriksson, Welander, & Granlund, 2007; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). In their study of teachers of students with either intellectual or physical disabilities (*n* = 1180 teachers), Simeonsson et al. (2001) found that students who were reported by their teachers to be more impaired and to have more functional limitations had lower levels of participation. In line with other studies showing a relationship between participation and QoL, these authors also found that higher teacher-rated participation in school activities was related to reports of higher student QoL. However, this study is limited by its sole use of teacher reports and by the possible confound of having the same respondents report on both participation and QoL. As described earlier, an individual who is deemed to have a deficit in some area of functioning may not in fact place a high level of importance on that domain, and thus, may not view the deficit as having an impact on his or her QoL (Fayed, 2011; Fayed, Schiariti, et al., 2011). In a mixed methods study involving the direct participation of children with (*n* = 33) and without (*n* = 33) disabilities, Eriksson et al. (2007) observed students at school over the course of a day and then interviewed them about their participation in activities both in and out of the classroom. The authors reported that the sample of children with disabilities (that included primarily motor impairment, but also intellectual disabilities, ADHD, Asperger syndrome, and visual impairment) experienced lower participation in activities structured by teachers (e.g., math, language arts, science) as well as in unstructured activities (e.g., recess, break times) as compared to children without disabilities. Social support was related to student engagement. For instance, children who reported having more friends who provided emotional support were more engaged than those who received less emotional support. Of note, peer support provided in both structured ($r = 0.427$, $p < 0.001$) and unstructured ($r = 0.350$, $p = 0.027$) situations was related to engagement in unstructured activities, suggesting that promoting positive peer relations among children with and without disabilities can have important consequences for student engagement in unstructured leisure activities. Although the sample size was small, this study's strengths lie in having a comparison group of typically functioning students, in conducting detailed observations, and most importantly, in soliciting the students' own perceptions of their participation.

More recently, in an effort to better understand the relationships between child participation, environments, and well-being, researchers have made explicit links to the ICF-CY. For instance, Leung, Chan, Chung, and Pang (2011) examined participation in a sample of preschool children with developmental delay ($n = 54$) and an age-matched control sample of children without disabilities ($n = 54$). All children were between the age of 5 years, 0 months and 5 years, 11 months and were recruited from integrated preschool programs in which children with disabilities are integrated with typically functioning students. Functioning was assessed using parent reports on the Kindergarten Sensory Integration Checklist, direct assessment by a paediatric occupational therapist using the Bruininks–Oseretsky Test of Motor Proficiency: Long Form, and teacher reports on the Conners' Teacher Rating Scale–Revised: Long Form. Activities and participation were assessed using teacher reports on the Vineland Adaptive Behavior Scales–Classroom Edition and on the School Function Assessment. Leung et al. found that children with developmental delays had lower levels of reported activities and participation as compared to typically functioning children ($p < .001$). Environmental factors were not significantly related to child participation. The authors explain this by the homogeneity of their sample; all children were attending government-funded preschools in Hong Kong that were required to provide a consistent level of programming and support. Child characteristics, such as motor and social skills, were significantly related to participation, with children who had lower reported functioning also reported as having lower levels of participation. The findings are not necessarily generalizable to the current North American research context; the experiences of children in Hong Kong may differ from those of children in North American preschools. Another limitation lies in the use of the Vineland Adaptive Behaviour Scales as a measure of child participation. This tool is most commonly used as a measure of adaptive functioning, thus its use by Leung et al. may confound child function with child participation.

The examples presented in the preceding paragraph highlight just some of the measurement challenges facing researchers who wish to examine the interrelationship between children's participation, well-being, and environmental constraints and supports impacting participation. Additional confusion surrounds the precise definitions of *activities* and *participation*, as these are grouped together in the ICF and ICF-CY and are only vaguely defined therein (Coster, Law, Bedell, Khetani, Cousins, & Teplicky, 2012). Fortunately, measures that examine child participation and enjoyment are emerging, and these hold tremendous promise for use with children with NDD. For instance, the Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004) was developed as a self-report measure of participation in recreation and leisure activities outside of school for children with and without disabilities. The validity of the CAPE has been established for children with physical disabilities categorized as either neurological or musculoskeletal (King et al., 2006) and is currently undergoing validation for use with children with NDD and for use with parents as proxies for their children (please see the Methods section for a detailed description of the CAPE). In their review of existing measures of children's participation and environments, Khetani, Bedell, Coster, Cousins, and Law (2012) found that many measures were long and took considerable time to complete and many were developed for use with children with physical disabilities. Recognizing the need for measures that can be used across a spectrum of childhood disorders, including intellectual disabilities, ADHD, ASD, and other cognitive or emotional conditions, Coster and her colleagues developed the Participation and Environment Measure for Children and Youth (PEM-CY; Coster et al., 2011; Coster et al., 2012). In addition to the length of the measure and its applicability to a range of childhood conditions, other important considerations for this team included being able to compare children and youth with and without disabilities, having a definition of participation that fit with how children perceive their own participation, and being able to link participation and environmental factors to the ICF-CY (Coster et al., 2012). The PEM-CY examines participation in three contexts: home, school, and community. Within each of these contexts consideration is given to environmental factors such as the adequacy and availability of opportunities for participation, as well as those things that facilitate or impede participation, such as physical barriers or attitudes and beliefs (Coster et al., 2012). The PEM-CY has undergone validation with a sample of parents of children with and without disabilities. The authors report that internal consistency was moderate to good (0.59 and above) and that test-retest reliability was also moderate to good over a one to four week period (0.58 and above), suggesting that the PEM-CY may be an appropriate tool for use in large-scale clinical and research contexts (Coster et al., 2011). Using the PEM-CY, Anaby and her colleagues (Anaby et al., 2014) investigated the role of the environment in mediating the relationship between child characteristics and participation. Parents of children with (*n* = 282) and without (*n* = 294) disabilities between the ages of 5 – 17 years completed the PEM-CY as well as a demographic questionnaire. The sample of parents of children with disabilities included parents of children with orthopaedic conditions, developmental disabilities, and speech/language disorders. Anaby et al. (2014) found that environmental barriers and supports were significant mediators between child characteristics (such as family income, health condition, and functional issues) and child participation across home, school, and community settings. The greatest impact of supports and barriers to participation was found in the community setting. The authors suggest that this may be due to families having less control in the community and therefore the environmental supports and barriers play a more important role in whether or not children are able to participate. These findings are in line with a scoping review of the literature that examined the role of the environment on participation (Anaby et al., 2013). Across 31 studies of children with disabilities (including cerebral palsy, physical disabilities, acquired brain injury, ASD, and Down syndrome) Anaby et al. (2013) found that what most facilitated child participation was social support from family and friends as well as geographic location (certain regions or countries were found to be more accessible, and these areas had higher participation). The greatest barriers to participation were found to be negative attitudes, physical accessibility, transportation, policies, and a lack of support from staff and service providers. These results suggest that there are many potential targets for improvement within community environments, the implementation of which would likely have a significant impact on the participation of children and youth with NDD in their communities.

Perceived need for and access to service. While the full impact of supports and services on the well-being of children with NDD is unclear, it appears as though the use of support is higher among families of children with NDD than among families of children without disabilities (e.g., Brehaut et al., 2004; Douma, Dekker, & Koot, 2006; Nachshen & Minnes, 2005). Moreover, the impact of supports and services on parent well-being has been studied and appears to have positive health benefits. Cowen and Reed (2002) examined parental stress before and after use of a respite program (n = 148 families, comprising 265 children with developmental disabilities; 98% of respondents were mothers). Parent stress decreased significantly following respite intervention (t = 3.27, df = 86, p = 0.0016). Similar findings are reported by Mullins, Aniol, Boyd, Page, and Chaney (2002) who compared the well-being of primary caregivers (n = 66 mothers, n = 3 fathers, n = 2 stepmothers, and n = 9 female guardians or relatives) following their children's participation in either a three- to seven-day in-patient respite program (n = 39) or a short-term (30 day) in-patient treatment program (n = 41). The respite program consisted of 24-hour nursing care and supervision by recreational therapy staff. No formal therapy was received by children in the respite program. The short-term in-patient treatment program consisted of comprehensive evaluation and treatment from medical services, nursing, physical therapy, speech therapy, occupational therapy, recreational therapy, social work, and psychology. Mullins et al. found that both groups of parents had significantly lower stress at discharge from their respective programs (*F*(1, 79) 7.21, *p* < .01, effect size = .08), and this was in spite of receiving different services (respite versus treatment) for different lengths of time (three to seven days versus 30). The authors concluded that these results support the utility of brief respite services in improving parent well-being. A lack of professional support has been found by other researchers to relate to parent functioning. In a sample of mothers of children with ASD (*n* = 21), severe psychomotor retardation (*n* = 20), Down syndrome (*n* = 20), and learning disabilities (*n* = 20), Ebert et al. (1989) found that a lack of support from professional services was a significant predictor of mothers' distress (R^2 = .092). In addition, a lack of professional services was also correlated with mothers' reports of an erosion of their social support (*r*(72) = .35, *p* = .010).

A number of studies report on the role of the perceived adequacy and/or quality of supports and services accessed by families of children with NDD. Looking at the relationship between informal social support and respite care in a sample of parents (93.1% mothers) of children with developmental disabilities (*n* = 72), Herman and Marcenko (1997) found that perceptions of the helpfulness of the parents’ informal social support was positively related to the reported quality of respite services used by the family (*r* = .30, *p* < .01) and perceptions of the helpfulness of informal social support was also negatively related to the frequency of respite use (*r* = -.24, *p* < .05), with parents who reported more helpful informal social support reporting less use of respite services. The findings also revealed correlations between parents' reported income resources and depression (*r* = -.39, *p* < .01) and between parents' time resources and depression (*r* = -.63, *p* < .01). Spratt, Saylor, and Macais (2007) used the Short Form of the Parental Stress Index to examine stress in mothers and fathers of children with combined developmental, behavioural, neurological, and emotional problems (DBC; *n* = 57), intraventricular haemorrhage documented at birth (IVH; *n* = 70), learning disability or attention deficit hyperactivity disorder (LD/ADHD; *n* = 54), or neural tube defects (NTD; *n* = 45). The results revealed that perceived adequacy of resources accessed by the family was a significant predictor of parent stress only in the IVH group, accounting for 30% of the variance for those parents. In the other groups the most significant predictors of parent stress were characteristics of the children, such as their intellectual functioning and behaviour problems.

Thompson, Lobb, Elling, Herman, Jurkiewicz, and Hulleza (1997) used path modelling to show that the more helpful support is perceived to be, as assessed by the Family Social Support Scale, the lower the family's stress, as assessed by the Questionnaire on Resources and Stress (beta weight = -0.60), and in turn, the more likely the family is to cope successfully with the challenges they face relating to their child with a NDD, as assessed through the family's level of empowerment (beta weight = -0.34). Similar models of family functioning, which posit the interactional relationship between various environmental and personal characteristics in family well-being in families of children with NDD, have been proposed by Hastings and Taunt (2002) and more recently by Greer, Grey, and McClean (2006). Greer et al.'s model is modified from the one proposed by Hastings and Taunt. Using a sample of mothers of young children with intellectual disabilities (*n* = 36), Greer et al. found that formal social support was a more effective form of support for these mothers than informal social support (range = 10.66 to 13.46, *M* = 11.8, *SD* = 0.70 and range = 10.00 to 15.00, *M* = 12.40, *SD* = 1.17, respectively). They further reported that the perceived helpfulness of formal social support predicted mothers' ability to mobilize access to supports in the community (ß = .42, sr^2 = .16, $p < .05$). The authors conclude that perceived helpfulness of social support might impact the mothers' coping resources, which would then impact their level of positive perceptions.

Summary

There is increasing empirical evidence that child functioning is related to parent well-being; parents of lower functioning children, who require more support in their day-to-day lives, have higher levels of stress and depression than parents of higher functioning children. Little is known about the relationship between child functioning and child well-being in children with NDD.

However, function has been identified as an indicator of health in the ICF (WHO, 2002), suggesting that this is an important relationship to explore. Therefore, the current study aims to inform public policy and clinical practice by examining the possible relationship between child functioning and child well-being in children with NDD. Better understanding of the complex needs of this population will not only inform policy and practice, but also represents a unique contribution to knowledge.

In keeping with the ICF mandate (WHO, 2002), an additional goal of this investigation is to identify gaps between children's capacity and their actual performance, and the role that supports and services can play in ameliorating the functioning, and subsequently the well-being, of these children and their families. The ultimate goal, then, is to inform policy initiatives that will influence the way in which services are implemented and clinicians practice. Before such change can come about, we must have a clear understanding of the factors influencing children's well-being. Although there is evidence that the well-being of parents is related to their need for and access to supports and services, the current literature contains no clear consensus as to whether a similar relationship exists for children. Therefore, the current investigation draws on a large and diverse sample of families of children with NDD (see methods section for included diagnoses) in order to explore the relationship between parents' perceptions of their children's and families' service needs and their children's well-being. In so doing, this study provides an original contribution to knowledge that will further our understanding of the needs of children with NDD, in order to facilitate the promotion of their well-being.

Chapter 3: Present Study

The present study is part of a larger research grant awarded to Dr. Lucyna Lach and her colleagues, entitled: *The CIHR Team in PARENTING MATTERS! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada* (Funding reference number: CWC94790). The goals of the larger project are to (a) better understand what it means to parent a child with a NDD, (b) identify key elements and processes of parenting a child with a NDD, (c) assess gender and role (e.g., mother/father) differences, (d) appreciate how intimate partnerships influence parenting, and (e) better understand parenting given the extraordinary circumstances that mothers and fathers of children with NDD face on a day-to-day basis. The goals of the present research are to (a) examine the factors that influence parent perceptions of well-being for their children with NDD and (b) contribute to the research design of the larger project through the addition of standardized measures of child cognitive and adaptive functioning, conducted with a subsample of participants.

Goal One (Hypothesis 1)

The first objective was to examine the factors that influence parent perceptions of their children's well-being. The proposed model (see Figure 1) shows the hypothesized relationships between parent perceptions of child functioning, supports and services, family socioeconomic status (SES), child age, and parent perceptions of child well-being. It was hypothesized that there would be a direct relationship between parent perceptions of child function and parent perceptions of child well-being; parents who perceived their children to be functioning well, as assessed by fewer reported concerns and difficulties, would report better well-being for their children than parents who perceived their children to have poorer functioning. It was also hypothesized that there would be an indirect relationship between parent perceptions of child function and child well-being, with supports and services acting to mediate the relationship. In this case, parent perceptions of child function would influence parent perceptions of child well-being through the extent to which their service needs are met. It was further hypothesized that supports and services would directly impact parent perceptions of their children's well-being. Parents who perceived the supports and services they received as meeting their needs and thus promoting their children's development and growth would be more likely to report better well-being for their children than parents who perceived the supports and services they received as failing to meet their needs. Finally, additional factors such as family SES and child age were hypothesized to influence parent perceptions of child well-being. It was expected that SES would directly impact child well-being such that lower family SES would be associated with lower child well-being. An indirect relationship between SES and well-being in which supports and services act as a mediator was also hypothesized; parents who had lower SES were expected to report more barriers to accessing supports and services, and in turn, to report lower well-being for their children. Child age was hypothesized to impact child well-being directly, as studies have shown child age to significantly impact child participation in and enjoyment of activities (e.g., Anaby et al., 2014). For instance, some studies have found that children between the ages of six and 12 show significantly higher rates of participation than older youth between the ages of 13-21. These findings have been associated with older adolescents' lower involvement in informal and recreational activities (Law et al., 2006) and with younger children's participation in a greater diversity of activities and at a higher intensity than older youth (Orlin, Palisano, Chiarello, Kang, Polansky, Almasri, & Maggs, 2010). Examining variability in activity participation for children within the six to 12 year age range, Majnemer et al. (2010) found that younger children showed a preference for activities of a more physical and skill-based nature which involved a self-improvement component (e.g., swimming lessons). Children across the six to 12 year age range showed equal levels of participation in social and recreational activities.

The independent variables in this model were parent reports of child functional difficulties, parent reports of the extent to which child and family formal support and service needs were met, SES, and child age. Child functioning was operationalized via two scores: the number of identified concerns on About My Child-26 (AMC-26; Rosenbaum et al., 2008) and the Total Difficulties Score on the Strengths and Difficulties Questionnaire (SDQ; Goodman, 2005). Higher scores on these measures represent more parental concerns about their children's functioning and thus, poorer parent perceptions of their children's functioning. The construct of supports and services was operationalized through the amount that both child and family needs are met. Two scores were derived from the Supports and Services Questionnaire (SSQ; Summers et al., 2005): one for child needs and one for family needs. Higher scores represent more unmet needs and lower scores represent fewer unmet needs. Family SES was operationalized through three variables: parent marital status, parent education, and household income.[4] Parent marital status was operationalized as a dichotomous variable: 1 = married or common law, 2 = separated, divorced, widowed, or single (never married). Parent education was operationalized as a dichotomous variable: 1 = completed university degree, 2 = did not complete university degree (includes some university, completed college or technical training, some college or technical training, completed high school, some high school, completed elementary school, and no schooling). Household income was operationalized as a dichotomous variable: 1 = $80,000 or more, 2 = $79,000 or less.[5] Child age was operationalized as the child's year of birth.

The dependent variables were child well-being and formal supports and services. Child well-being was operationalized through three scores: Being, Belonging, and Becoming on the Quality of Life for Children with Developmental Disabilities: Parental Perspective (QLCDD; Renwick et al., 2004). As described above, supports and services was operationalized through the amount that both child and family needs are met, according to parent reports on the SSQ.

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[4] There were several reasons for using dichotomous SES variables. First, sample size constraints meant that using the full range of SES response choices from the parent questionnaires would have resulted in some groupings having too few participants to allow for appropriate analysis (e.g., "no schooling"). Second, the income categories were fine grained up to $110,000, but all incomes above this value were categorized as "more than $110,000." Many respondents fell into this undifferentiated highest category. Therefore, grouping all participants in that final category and comparing them with, for instance, all those who reported earning $10,000 or less would have presented a different false dichotomy. Finally, the sample size constrained the number of SES variables that could be entered into the SEM, making dichotomous groupings the only feasible option.

[5] The rationale for selecting "$80,000 or more" and "$79,000 or less" as the dichotomous income variables was based on 2011 mean after tax Canadian household income of $79,600 for economic families comprising two or more persons (Statistics Canada, 2013).

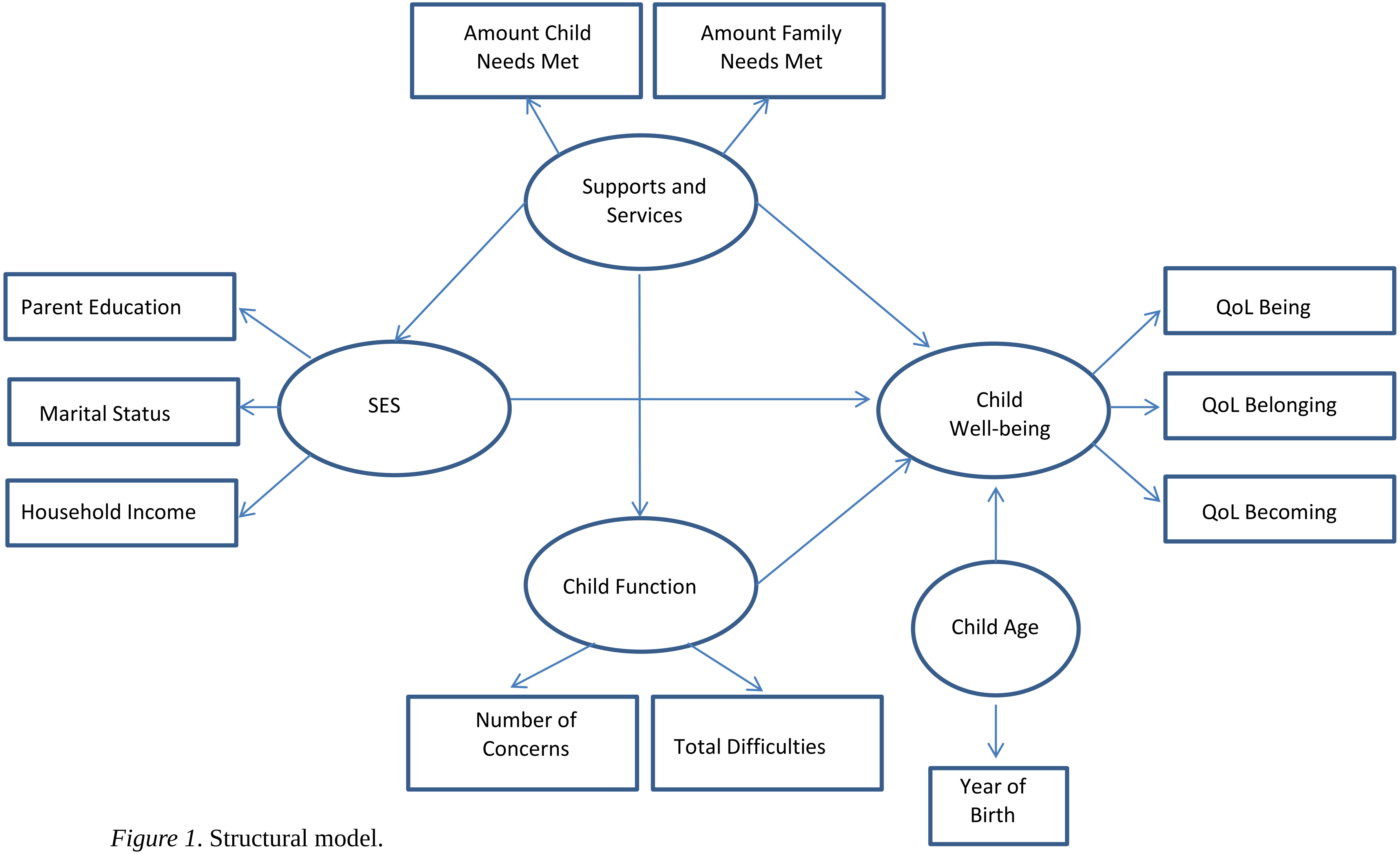

Figure 1. Structural model.

Goal Two

The second objective was to contribute to the research design of the larger study through the addition of two standardized measures of child function, administered with a subsample of children.

Hypothesis 2. It was hypothesized that AMC-26, which was used in the larger study as a measure of child function, and was undergoing validation at *CanChild*, would be a valid parent-report measure of child function for children with NDD.

a. It was hypothesized that AMC-26 would show good internal consistency of the scale items, as assessed through Cronbach’s alphas calculated on the overall sample.
b. It was hypothesized that AMC-26 would show good convergent validity of the scale domains through comparison with existing standardized measures of cognitive function, Stanford-Binet Intelligence Scales, Fifth Edition (SB5; Roid, 2003), and adaptive function, Vineland Adaptive Behavior Scales-II, Survey Interview Form (Vineland-II; Sparrow, Cicchetti, & Balla, 2005) administered with a subsample of children as well as good convergent validity with an existing measure of child behaviour problems (SDQ) administered with the full sample from the larger study.
c. Given the literature showing a relationship between child function and parent well-being, it was hypothesized that scores on AMC-26 would correlate positively with parent depressive symptoms as assessed by the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977).

Hypothesis 3. It was hypothesized that parents' perceptions of their children's functioning would mediate the relationship between children's functioning as assessed by standardized measures of cognitive and adaptive functioning and parent perceptions of their children's well-being.

The independent variables in this hypothesis were child cognitive and adaptive functioning. Cognitive functioning in this case was operationalized by the Full Scale IQ on the SB5. Adaptive functioning was operationalized by the Adaptive Behavior Composite on the Vineland-II. The dependent variable was child well-being, which was operationalized in the same way as in Goal

One (through three scores: Being, Belonging, and Becoming on the QLCDD) and additionally, through the Overall Diversity Score on the Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004). The mediating variable was hypothesized to be parent-reported child functioning. This variable was operationalized as the number of identified concerns on AMC-26. Higher scores on AMC-26 represent more parental concerns about their children's functioning and thus, poorer parent perceptions of their children's functioning (see Figure 2 for diagrams of the paths that were tested).

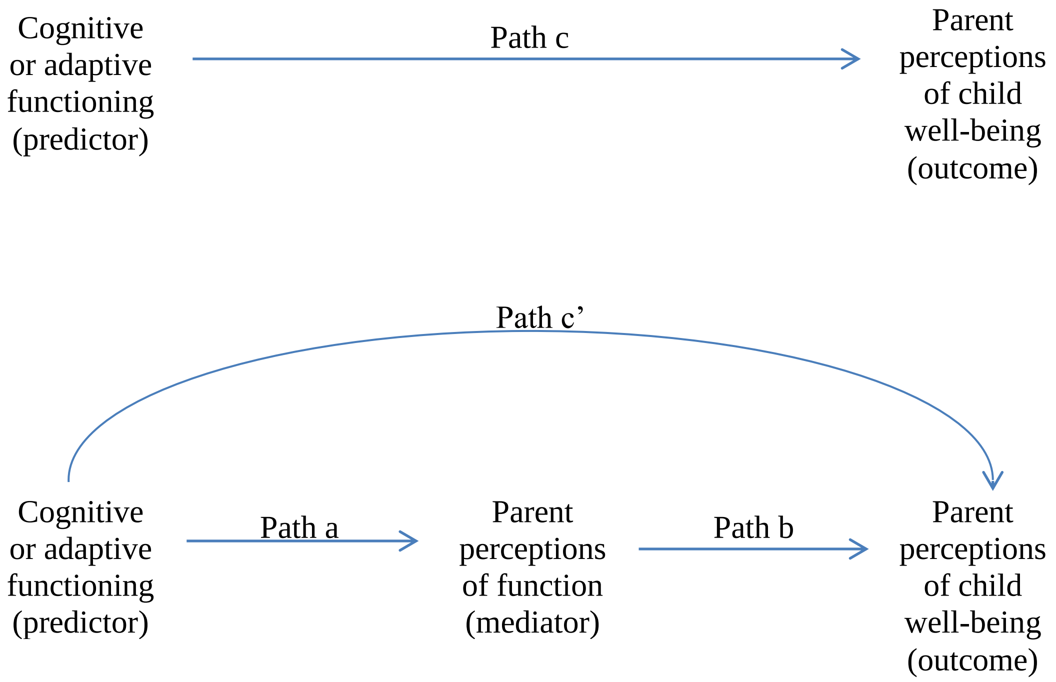

Figure 2. Diagrams of the paths tested in the mediation analysis.

Method

Design. In the current project child well-being is defined as:

> …contentment, satisfaction, or happiness derived from optimal functioning. This need not imply perfect function; it is subjective and is a relative, rather than an absolute, concept. The reference point for judging well-being is [the] person's own aspirations, based on a blend of objective reality and their subjective reactions to it. (McDowell, 2010, p. 70)

Following from this definition, the construct of child well-being was operationalized and measured by the QLCDD, and for selected hypotheses, also by the CAPE. Together, these two measures of child well-being formed the dependent variable. Psychometric properties of these measures are presented later in this section.

Child and environmental variables were examined in order to assess their impact on child well-being. Child functioning was evaluated using AMC-26, which provides information about the functional needs of children and priorities of families and can also assess the complexity of child functioning; the SDQ, which is a behavioural screening questionnaire that addresses emotional symptoms, conduct problems, hyperactivity and inattention, peer relationship problems, and prosocial behaviour; the SB5, which is a standardized measure of cognitive functioning; and also using the Vineland-II, a standardized measure of adaptive functioning administered through a structured interview with parents. Parent perceptions of the extent to which the service needs of their children and their families were met were assessed using the SSQ. Parent depressive symptoms were assessed using the Center for Epidemiologic Studies Depression Scale (CES-D). Psychometric properties of these measures are presented later in this section.

Participants and recruitment. Participants were caregivers, primarily mothers, of children with NDD who were between the ages of 3 and 13 (*M* = 8.18 years, *SD* = 2.51). The present study subscribed to a non-categorical approach to childhood disability in which NDD was broadly defined as any disorder in which motor, cognitive, behavioural, and/or language functioning are affected by central nervous system impairments (Farmer & Deidrick, 2006). Participants were recruited from children's hospitals and treatment centres in Quebec, Ontario, and Alberta. In all, 15 centres participated in the Parenting Matters! investigation: Montreal Children's Hospital (Montréal, Québec), Jewish Rehabilitation Hospital (Montréal, Québec), MAB-Mackay Rehabilitation Centre (Montréal, Québec), Shriner's Hospital (Montréal, Québec), West Montreal Readaptation Centre (Montréal, Québec), Miriam Home (Montréal, Québec), Grandview Children's Centre (Oshawa, Ontario), Holland Bloorview Kids Rehabilitation Hospital (Toronto, Ontario), the Hospital for Sick

Children (Toronto, Ontario), Surrey Place Centre (Toronto, Ontario), Erinoak Kids Centre for Treatment and Development (Mississauga, Ontario), McMaster Children's Hospital (Hamilton, Ontario), Alberta Children's Hospital (Calgary, Alberta), Glenrose Rehabilitation Hospital (Edmonton, Alberta), and Stollery Children's Hospital (Edmonton, Alberta). Recruitment occurred between July 2011 and January 2014, although recruitment periods differed in timing and length across the sites. Recruitment was done via convenience sampling; caregivers were invited to participate by a familiar health care provider and interested parents were subsequently given additional information and invited to consider consenting to participate by one of the Parenting Matters! study research assistants. The inclusion criteria for parents was that their child's primary diagnosis was indicative of a NDD, the diagnosis was made a minimum of six months before their entry into the study (in order to exclude participants experiencing high levels of emotional distress immediately following the diagnosis), and their child with NDD was between four and 12 years of age (although one child was three years old, and a few children turned 13 between the time of recruitment and study completion). In addition, parents had to be able to read at a Grade 5 level in English. In all, 629 caregivers indicated that they were interested in participating in the study. Of these, 563 signed consent forms agreeing to participate. The final data set comprised 263 caregivers[6] (*n* = 198 mothers; *n* = 52 fathers; *n* = 13 others, including adoptive and foster parents, relatives, and group home workers) of 238 children (*n* = 91 female, *n* = 147 male; see Table 1 for caregiver and child ages). Children's diagnoses were obtained by parent report. The most

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[6] There are several possible explanations for the high attrition rate from this study. First, most participants signed consent forms during or immediately following their child's medical clinic visit. It is possible that although parents were repeatedly told that they were under no obligation to participate and that their child's clinical care would in no way be impacted by their decision to participate or not, parents may have felt social pressure to appear "good" in the eyes of their medical providers. In such cases, parents may have enrolled without having true intentions of participating. In fact, a large number of participants who chose to respond via the web-based survey never once logged on. Similarly, a large number of participants failed to respond to voice mail and email messages reminding them to complete their questionnaires. Second, the package of questionnaires was large and parents reported that completing them took a considerable amount of time (typically between two to four hours, although several parents reported that it took them much longer than this). Most participants who officially withdrew from the study cited time constraints as their reason for being unable to continue participating. Similarly, examination of incomplete on-line survey responses revealed many participants who completed earlier sections of the study protocol, but failed to complete the full set of questionnaires. Finally, as outlined in earlier sections of the current paper, the population of parents from which the current sample was obtained is known to experience significant levels of stress and to face many parenting challenges related to the complexity of their children's conditions. Therefore, it is possible that the demands of the current study were simply too high given the daily challenges faced by many of these families.

commonly reported diagnoses were cerebral palsy (CP; *n* = 73), autism spectrum disorders (ASD; *n* = 46), and seizure disorder (including epilepsy and Dravet spectrum disorder; *n* = 33), while the remaining 87 participants were reported to have various other NDD such as chromosomal variants and cerebral malformations. In addition, 88 children were reported to have a comorbid diagnosis (seizure disorder, *n* = 30; ASD, *n* = 14; CP, *n* = 4; other, *n* = 40) and of those, 25 children were reported to have two or more comorbid diagnoses. There are a number of parental and clinical realities that make this kind of counting challenging. First, from a parent's perspective the nuances of which specific kind of NDD like 'CP' or 'epilepsy' their child has may not be important, once the diagnostic work-up has been done. Most parents will be concerned with issues of treatment, management and prognosis and be less interested in biomedical nosology and subtyping. Second, it is also well recognized that many of these diagnoses are associated with diverse manifestations of these biomedical impairments. Therefore, without access to full medical charts and reliance on parent report, collection of an exhaustive list of diagnoses was not possible. For this reason the main diagnoses reported by parents have been reported (see Table 2 for a complete breakdown of diagnoses). Family sociodemographic characteristics are reported in Table 3. Participants were provided an honorarium of a $25 gift certificate to a local retail establishment upon completion of the parent survey.

Table 1

Caregiver and Child Ages

	n	*M*	*SD*
Caregiver			
Mother	194	42.16	6.11
Father	52	44.96	6.92
Other	13	52.19	13.25
Child			
Female	91	8.25	2.54
Male	147	8.13	2.49

Note. Caregiver ages are approximations based on year of birth and date of study completion.

Table 2

Child Diagnoses (primary)

Diagnosis	%
Cerebral palsy	30.7
Autism spectrum disorder	19.3
Seizure disorder	13.9
Down syndrome	3.4
Global developmental delay	2.9
Developmental disability	2.5
Stroke	2.1
Acquired brain injury	1.7
Tuberous Sclerosis	1.7
Undisclosed diagnosis	1.7
Attention deficit hyperactivity disorder	0.8
DiGeorge syndrome	0.8
Mild intellectual disability	0.8
Nonverbal learning disability	0.8
Osteogensis imperfect	0.8
Periventricular leukomalacia	0.8
Prader-Willi syndrome	0.8
Rett syndrome	0.8
Williams syndrome	0.8
Acute transverse myelitis	0.4
Aicardi Goutieres syndrome	0.4
Alternating hemiplegia of childhood	0.4
Angelman syndrome	0.4
Apnea disorder	0.4
Brain lesion left frontal lobe	0.4
Brain tumour	0.4
Cerebral dysgenesis	0.4
Clinical AS	0.4
Dyslexia	0.4
L1 syndrome	0.4
Lennox Gastaut syndrome	0.4
Microcephaly	0.4
Muscular Dystrophy	0.4
Oculodentodigital dysplasia	0.4
Oppositional defiant disorder	0.4
Phelan-McDermid syndrome (22q13 deletion)	0.4
Pitt-Hopkins syndrome (chromosome 18 deletion)	0.4
Unbalanced chromosomal translocation	0.4
Chromosome 17 deletion	0.4
8p syndrome (chromosome 8p deletion)	0.4
Porencephaly	0.4
Post CVH	0.4
Schizencephaly	0.4
Semi-lobar holoprosencephaly	0.4
Severe hydrocephaly	0.4
Severe neurodevelopmental disorder	0.4
Speech delay	0.4
Unknown diagnosis	0.4
Wolf-Hirschhorn syndrome	0.4

Table 3

Family Sociodemographic Characteristics

	n (% of valid *n*)					
Characteristic	Mother		Father		Other	
Marital Status						
Single (never married)	9	(4.5)	1	(1.9)	1	(7.7)
Widowed	1	(0.5)	1	(1.9)	1	(7.7)
Divorced	9	(4.5)	1	(1.9)	2	(15.4)
Separated	14	(7.1)	1	(1.9)		
Common Law	13	(6.6)	4	(7.7)	1	(7.7)
Married	152	(76.8)	44	(84.6)	8	(61.5)
Family Structure						
Single parent family	32	(16.2)	3	(5.8)	3	(23.1)
Two parent family	163	(82.3)	48	(92.3)	5	(38.5)
Other	3	(1.5)	1	(1.9)	5	(38.5)
Highest level of education						
Some high school	6	(3.0)	2	(3.9)		
Completed high school	10	(5.1)	7	(13.7)		
Some college or technical training (at least 1 year)	20	(10.2)	5	(9.8)	1	(7.7)
Completed college or technical training	59	(29.9)	14	(27.5)	5	(38.5)
Some university (at least 1 year)	8	(4.1)	2	(3.9)	4	(30.8)
Completed university degree	94	(47.5)	21	(41.2)	3	(23.1)
Community type						
Large metropolitan	85	(42.9)	20	(38.5)	1	(7.7)
Medium metropolitan	30	(15.2)	3	(5.8)	5	(38.5)
Non-metropolitan less urbanized	19	(9.6)	4	(7.7)		
Non-metropolitan urbanized	15	(7.6)	8	(15.4)	2	(15.4)
Rural	12	(6.1)	5	(9.6)		
Small metropolitan	36	(18.2)	9	(17.3)	5	(38.5)
Other	1	(0.5)	3	(5.8)		
Household income						
Less than $10,000	6	(3.2)	3	(5.9)	1	(7.7)
$10,000 to $19,000	10	(5.2)	3	(5.9)		
$20,000 to $29,999	11	(5.8)	3	(5.9)		
$30,000 to $39,999	12	(6.3)	4	(7.8)	3	(27.3)
$40,000 to $49,999	9	(4.8)	2	(3.9)	2	(18.2)
$50,000 to $59,999	10	(5.3)	2	(3.9)	1	(9.1)
$60,000 to $69,999	14	(7.4)	5	(9.8)	3	(27.3)
$70,000 to $79,999	15	(7.9)	5	(9.8)		
$80,000 to $89,999	8	(4.2)	3	(5.9)		
$90,000 to $99,999	12	(6.3)				
$100,000 to $109,999	18	(9.5)	5	(9.8)		
More than $110,000	64	(33.9)	16	(31.4)	1	(9.1)

A subsequent convenience sample was recruited from the larger study in order to test Hypotheses 2 and 3. A target sample size of 50 participants was set for this subsample, given a minimum ratio requirement of 20 cases for every independent variable in the model (Tabachnick & Fidell, 2007), and following expert consultation (N. C. Hall, personal communication, December 5, 2011) and analysis of sufficient power. Parents who, on the initial consent form, indicated that they would be willing to participate in other related research were contacted by phone or by email and were invited participate in the child cognitive and adaptive assessment. Assessments were conducted by the primary investigator (A.R.) in participants' homes between July 2012 and April 2014. Initial sampling was based on participants' geographic proximity to the primary investigator, and was therefore limited to the City of Toronto. Subsequently, recruitment for the child assessment study was broadened in order to attain the desired sample size. At this stage, participants living as far east as Oshawa, as far north as Barrie, as far west as Brantford, and as far south as Niagara Falls were invited to participate. Efforts were made to achieve sampling variation and heterogeneity among families across child age and diagnosis. However, given the added time demands for families who participated in this second phase of research, as well as the geographical limitations described above, it was anticipated that the make-up of this second sample might be different from that of the larger study sample. For instance, parents who were too stressed and overwhelmed by the responsibilities they faced relating to their child with NDD may have been less willing to participate. On the other hand, if parents perceived that they might benefit from the second phase of the study (in terms of receiving additional testing and the subsequent written report of their child's functioning), then it might have been parents who felt that the services they received were inadequate who might have been more willing to agree to participate. Thus, it was anticipated that the second sample would be more likely to include families who were at the extreme ends of the distribution of participants in terms of their overall well-being and in terms of the adequacy of the supports and services they were receiving. In order to account for these possible differences between the main sample and the second sample, these variables were examined prior to hypothesis testing.

In all, 86 families were invited to participate in the follow-up study, with 50 families consenting to participate. Assessments were completed with all 50 families, although one parent's set of questionnaires from the larger study were lost and her son's follow-up results were therefore discarded from the analyses, leaving a sample size of 49 children (*n* = 19 female, *n* = 30 male) and their parents. Those families who participated in the child cognitive and adaptive functioning assessment received a written report of their children's results from the assessment, as well as a second honorarium of $25 to a local retail establishment. Participating children were offered stickers and small toys following their participation in the testing. The study received approval from the Human Subject Research Ethics Board at the University level and from the individual centres and hospitals from which participants were recruited.

Standardized questionnaires. Participating parents completed two packages of questionnaires addressing salient factors/domains. Participants were offered the option to receive the survey in two instalments or as one complete package, and most chose to receive the complete package and to work through it at their leisure. Research assistants were available to assist participants in completing the survey, should participants have desired. Questionnaires were available in a paper copy or online.

Child assessment and parent interview. The principal investigator contacted those families who consented to be contacted in the future. If the family consented to participate in the current study, the principal investigator scheduled both a child assessment session and a parent interview session that were convenient for the family. Child testing occurred in the participants' homes. A quiet, distraction-free testing environment was sought, whenever possible. The principal investigator has received extensive training in the administration of psychological tests, and in particular received training to administer the SB5. The principal investigator's training includes completion of two foundational courses in psychological testing and assessment[7] as well as two years of supervised assessment training through McGill Psychoeducational and Counselling Clinic,[8]

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[7] Psychological Testing 1 (EDPC 609) and Psychological Testing 2 (EDPC 610) which covered theoretical aspects of individual and group testing, validity, reliability, and test construction, basic theories of intelligence, and ethical and legal issues in testing. The courses also provided an introduction to tests of cognitive abilities, aptitude, personality, and interests, including the acquisition of basic skills needed to administer and interpret individual tests of cognitive abilities.

[8] Practicum: Psychological Testing (EDPC 682D1and EDPC 682D2) which was a two-part seminar and field practice in the administration and interpretation of educational and psychological tests including personality, within clinical and educational settings. Selection and evaluation of test instruments was covered as was the ethical use of test information. Supervision was provided for report writing. Practicum 1: School Psychology (EDPE 625) and Practicum 2: School Psychology (EDPE 626) included clinic experiences (normally 8-10 hours/week) (a) conducting assessment batteries, (b) interpreting assessment findings and developing intervention plans, (c)

and two years of supervised field training at Surrey Place Centre, which occurred concurrently with data collection. All children were first assessed using the Abbreviated Battery IQ of the SB5, which took approximately 20 minutes. Depending on the children's level of functioning and performance during testing, additional components of the SB5 were administered. For instance, where ability level allowed, the Full Scale IQ was administered. If children had orthopaedic limitations, then only the Verbal IQ was administered following the Abbreviated Battery IQ (this modification applied to only one child who was unable to participate in the full cognitive assessment). The Vineland-II interview with parents took place either in person or over the telephone, whichever the parents preferred. In addition to the clinical training described above, the primary investigator has received extensive training in the administration of the Vineland-II and had prior research experience conducting the Vineland-II interview with parents of children with NDD (*n* = 26). Each Vineland-II interview with parents took between 30 to 60 minutes to complete.

Materials.

About My Child, 26-item Version (AMC-26; Rosenbaum et al., 2008). AMC-26 was used to assess parent perceptions of their children’s functioning. AMC-26 is a 26-item parent report scale that serves as a tool for understanding the functional needs of children and priorities of families. Respondents are directed to answer each question with reference to a guiding statement: “Compared to other children of the same age, I am concerned about my child’s...” Response options are “yes” or “no.” If participants select “yes” they are directed to rate the impact of the functional limitation on their child's ability to participate in everyday activities. Possible impact ratings are: Not at all; A little; Somewhat; or A lot. The scale is divided into nine subdomains: mobility, daily activities, ability to communicate, behaviour, mood, thinking and learning abilities, social skills with children, social skills with adults, and participation in outside activities. A complexity score is generated by summing the number of identified functional concerns (items

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providing remedial services for specific learning domains and practical recommendations, (d) acquiring skills in group intervention techniques. Weekly case review and student progress meetings were a central component of the courses.

endorsed with a “yes” answer). The impact score is obtained by assigning numeric values to the four impact response choices (ranging from zero to three) and then calculating the mean. The authors state it is important to understand the functional needs (complexity) of childhood disability because this information can be used to forecast service planning needs and allocate resources more efficiently. The current study used the complexity score as a tally of parents’ functional concerns about their children. AMC-26 is currently undergoing validation through the *CanChild* Centre for Childhood Disability Research at McMaster University. See the Appendix A for items.

Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). The CES-D was used to assess parent depressive symptoms as part of the testing of Hypothesis 2. The CES-D is a 20-item self-report measure of current depressive symptoms that is appropriate for use with both clinical and general populations (Radloff, 1977) and takes approximately five minutes to complete (Yonkers & Samson, 2000). The CES-D items were derived from existing validated measures of depression, including the Zung Self-Rating Depression Scale, the Beck Depression Inventory, the Raskin Scale, and the Minnesota Multiphasic Personality Inventory Depression Scale (Radloff, 1977; Yonkers & Samson, 2000). The CES-D was not designed as a diagnostic tool for depression but rather as a short measure to assess current depressive symptomatology, with an emphasis on depressed mood. Therefore, the major components of depressive symptomatology included in the CES-D are: depressed mood; feelings of guilt and worthlessness; feelings of helplessness and hopelessness; psychomotor retardation; loss of appetite; and sleep disturbance (Radloff, 1977). In order to elicit current feelings, respondents are asked to answer questions based on the way they have felt during the past week. The rating scale goes from zero (“Rarely or none of the time” or less than 1 day out of the past 7 days) to three (“Most or all of the time” or 5 to 7 days out of the past 7 days). Thus, scores can range from 0 to 60. Four of the questions are worded positively in order to control for response bias and to assess positive affect. Although factor analysis identified four factor loadings (depressive affect, positive affect, somatic and retarded activity, and interpersonal), it is advised that only a total score be calculated (Radloff, 1977). To calculate the total severity score, scores on positive items 4, 8, 12, and 16 are reversed and then all item scores are summed. A score of 16 or higher has been identified as a cut-off for identifying individuals with clinical levels of depressive symptoms (Yonkers & Samson, 2000). The present study used the total severity score as an indicator of parent depressive symptoms.

Reliability of the CES-D is reported to be good (Radloff, 1977; Yonkers & Samson, 2000). Internal consistency was found to be high in both the general population (Cronbach's alpha approximately .85) and in clinic patients (Cronbach's alpha approximately .90). Split-half reliability ranged from .77 to .92, which is also high. Test-retest reliability was moderate for two to eight week intervals (r = .51 - .67). Several factors impacted the likelihood of obtaining strong test-retest reliability correlations for the CES-D. For instance, depressive symptoms are expected to vary over time, yet the CES-D is designed to measure current symptomatology. Therefore, it is expected that individual ratings may fluctuate over time. In addition, negative life events are likely to impact the stability of responses over time. Radloff (1977) reports that individuals who had not experienced any negative life events in the past year did in fact have higher test-retest correlations than individuals who had experienced negative life events.

The validity of the CES-D is reported to be reasonable (Radloff, 1977). The measure successfully discriminated between clinical samples and the general population, with 70% of clinical participants scoring above the cut-off of 16 while only 21% of participants in the general population scored above the cut-off. Furthermore, in the clinical samples CES-D scores decreased significantly following treatment, as did scores on other measures of depression. Nevertheless, when CES-D scores were compared with existing measures prior to treatment, correlations were more variable (Yonkers & Samson, 2000). For instance, in samples of outpatients with depression, alcoholism, drug addiction, or schizophrenia, correlation coefficients between CES-D scores and scores on the Symptom Checklist – 90 (SCL-90) Depression subscale were high (0.73 to 0.89), whereas on the Hamilton Rating Scale for Depression (Ham-D) scores were variable (0.49 for depression; 0.85 for schizophrenia). Similar variability has been reported across different populations and with different measures of depression, supporting the authors' assertion that the CES-D is not a measure of depression but is instead a measure of psychological distress (Yonkers & Samson, 2000).

Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004). The CAPE was used to assess child well-being as part of the testing of Hypothesis 3. The CAPE is a 55-item parent-report measure of children's participation in recreation and leisure activities outside of school. The measure is appropriate for use with individuals from 6 to 21 years of age, either with or without disabilities. There are five dimensions of participation covered by the CAPE: diversity (number of activities), intensity (frequency of participation), enjoyment, and context (which makes up dimensions four and five as it includes questions that address both with whom children participate and where). The current study used the overall diversity score as an indicator of child well-being. The CAPE takes between 30 and 45 minutes to complete.

Scoring for the CAPE is done along three levels: overall participation scores, scores for formal and informal activities, and scale scores for five types of activities (recreational, active physical, social, skill-based, self-improvement). Formal activities are those activities that are structured, have rules, and are often led by either instructors or coaches. Informal activities are less structured and are typically not planned, for example playing with friends. These three scores can be computed for each of the five dimensions described above (Imms, 2008; King et al., 2004; King et al., 2006).

The CAPE was developed following an extensive search of the literature, an expert review process, and pilot testing of the measure (Imms, 2008). The literature review covered four areas of research: rehabilitation literature on participation of children and adults with disabilities; psychology literature on risk and resilience of children facing adversity; the recreation literature on determinants of leisure and recreation activities; and the general literature on factors influencing physical activity and exercise (Imms, 2008; King et al., 2003; King et al., 2004). Results of this review suggest that the factors that influence children’s participation include how physically accessible and welcoming the environment is, the family's income and family functioning, and child cognitive ability and social skills (King et al., 2003). Subsequent to the review of the literature, King and her colleagues proposed a conceptual model of those factors thought to influence the participation of children with disabilities. The model suggested that children's participation is influenced by children's functioning, by characteristics of their parents, and by the environment, and that these factors interact in complex ways (King et al., 2003). Given that no other measures exist that assess child participation, a primary aim in the development of the CAPE was to provide such a measure. The authors state that it is only through a comprehensive understanding of the multiple factors affecting child participation that appropriate intervention can be planned and that policy development can be effected at the systems level (King et al., 2003).

The reliability and validity for the CAPE were established through a three-year longitudinal study of children with physical disabilities in the province of Ontario (*n* = 427). All children were between the ages of 6 and 15 years. Their disorders were categorized as either neurological or musculoskeletal and resulted in physical impairment. The original 49-item CAPE was used for the longitudinal study and was administered in two phases, three weeks apart. In phase one, families were mailed the self-report response booklet form of the CAPE. Children completed the questionnaire themselves, receiving help from their parents if they required. In phase two, three weeks after phase one, an interviewer completed the interview version of the CAPE with the children, focusing just on the activities in which the children reported participating at phase one. In reference to the child-reported activities, interviewers administered the with whom, where, and amount of enjoyment sections of the CAPE (King et al., 2006).

To assess the construct validity of the CAPE, several predictions were made based on relevant research literature, as no comparable tests exist that assessed children's participation (King et al., 2006). First, it was predicted that the intensity of participation in recreational activities would be associated with the family's active recreational orientation, defined as the family's participation in social and recreational activities. Second, it was predicted that the intensity of participation in active physical activities would be associated with parents' perceptions of barriers in the physical-structural environment, with family income and financial constraints, with family time constraints, with the family's active recreational orientation, and with the children's health and athletic ability. Third, it was predicted that the intensity of participation in social activities would be associated with children's perceptions of the support they received from their classmates and friends, with the family's active recreational orientation, with the children's social competence, their prosocial behaviour, and their social-emotional-behavioural functioning, and with the children's communicative functioning. Fourth, it was predicted that the intensity of participation in skill-based activities (e.g., playing a musical instrument) would be associated with the family's active recreational orientation and with the family's intellectual-cultural orientation, defined as the family's level of interest in political, intellectual, and cultural activities. Finally, it was predicted that the intensity of participation in self-improvement activities, such as reading, would be associated with the family's active recreational and intellectual-cultural orientations and also with the children's cognitive and communication functioning. King and her colleagues found that all predicted relationships were significant at the $p < .01$ level and ranged from 0.10 to 0.20. The authors note that these correlations are smaller than expected, but nonetheless significant (King et al., 2006).

Internal consistency of the CAPE frequency scores was determined for each domain (formal activities and informal activities) and each of the five activity types (recreational, active-physical, social, skills-based, and self-improvement). The Cronbach's alpha values at the first scoring ranged from a low of 0.32 for skill-based frequency to a high of 0.76 for informal activities frequency. The variation in the alpha values between the first scoring and the second scoring was not significant (Imms, 2008; King et al., 2004).

Using a sample of children aged 6 to 14 years ($n = 48$) the authors assessed the test-retest reliability of the CAPE via two separate administrations, three weeks apart. The Interclass Correlation Coefficients were found to be between 0.67 and 0.86 for all of the diversity and intensity scores. These values are reported to be adequate, as values between .70 and 0.90 are considered appropriate (King et al., 2004; Portney & Watkins, 2000). Please see PDF attachment for items.

Quality of Life for Children with Developmental Disabilities: Parental Perspective (QLCDD; Renwick et al., 2004). The QLCDD questionnaire was used as a second indicator of child well-being. The QLCDD is a 50-item parent-report measure appropriate for use with parents of children aged three through 12 years who have a developmental disability. This questionnaire goes beyond traditional health-based conceptualizations of quality of life and is based on a multidimensional and holistic theoretical framework of quality of life, developed by the Quality of Life Research Unit at the University of Toronto (Renwick, Fudge Schormans, & Zekovic, 2003). Three different elements influence children's quality of life: the child, the child's parental and family environment, and the broader environment in which the child lives. A child's quality of life is thus based on the degree of "fit" (overlap) between these three elements. With better fit, the child experiences a better quality of life. When the fit between the elements is poorer, the child's quality of life is lower (Renwick et al., 2003; Renwick & Fudge Schormans, 2004). The QLCDD examines three different domains: Being, Belonging, and Becoming. The Being domain measures who the child is perceived to be, specifically whether the child is viewed first and foremost as a child, or whether his or her disability is seen first. The Belonging domain assesses the child's connections to people and places, for example, the extent to which the child's environment is secure and nurturing as well as the extent to which individuals in the child's environment understand the child and have positive interactions with him or her. Finally, the Becoming domain examines the child's nurtured growth and development, in particular the extent to which the child's current needs are met. Each of the 50 items is rated on three scales: Applies, Importance, and Satisfaction, using a five-point rating scale with equal-appearing intervals. Scores for each rating scale can range from 1 (does not apply/ not at all important/ not at all satisfied) to 5 (applies very much, extremely important, extremely satisfied; Renwick et al., 2003; Renwick & Fudge Schormans, 2004).

Psychometric validation of the QLCDD was achieved using a sample of 186 participants (parents of children aged three to 12 with a developmental delay or disability), recruited through over 50 community-based organizations that provide developmental services and/or education in the province of Ontario. Parents completed a 48-item version of the QLCDD, the Family Information Questionnaire (a socio-demographic instrument), the WeeFIM Instrument (a measure of function), and the 28-item version of the Children's Health Questionnaire – Parental Form (a measure of health-related quality of life; Renwick & Fudge Schormans, 2004).

The internal reliability of the QLCDD was assessed using Cronbach's reliability analyses. The alpha coefficients for the nine domain scores (Being, Belonging, and Becoming, each measured in terms of Applies, Importance, and Satisfaction) were all between .39 and .91. The alpha coefficients for the three total scores were between .89 and .95. Overall, 10 of these 12 coefficients exceeded .70, which is the criterion for acceptable internal reliability (Renwick & Fudge Schormans, 2004).

The test-retest reliability of the QLCDD was assessed using subsample of 10 parents who completed the measure on two occasions, 12-16 days apart. Pearson correlations between time one and time two scores for the 9 domain scores were between .24 and .90, with the majority (seven) equal to or greater than .74, which is significant at $p < .05$. The coefficients for the three total scores ranged from .73 to .80.

The concurrent validity of the QLCDD was evaluated by comparing it with both the WeeFIM Instrument and the Children's Health Questionnaire. As the QLCDD was designed to assess different aspects of quality of life than either the WeeFIM Instrument or the Children's Health Questionnaire, weak correlations were hypothesized. In accordance with this hypothesis, most correlations between the QLCDD and the other two measures were weak across overall scores and individual subdomains.

Construct validity was assessed through a series of confirmatory factor analyses using both varimax and oblique rotation techniques. The results confirm the theoretical factor structure of the instrument and support the inclusion of the items associated with the Being, Belonging, and Becoming. Please see Appendix B for items.

Stanford-Binet Intelligence Scales, Fifth Edition (SB5; Roid, 2003). Child cognitive functioning was assessed in a subsample of children using the SB5. The SB5 is an individually administered assessment of intelligence and cognitive abilities. The SB5 is normed for use with individuals aged 2 through 85 years. Administration of the Full Scale IQ takes between 45 and 75 minutes, while administration of the Abbreviated Battery IQ takes between 15 and 20 minutes. The SB5 also includes separate Nonverbal IQ and Verbal IQ sections, which each take approximately 30 minutes to administer. The Full Scale IQ is obtained by administering 10 subtests and is considered the standard measure of global intellectual functioning. The Abbreviated Battery IQ is obtained from the Object Series/Matrices and Vocabulary routing subtests. The Nonverbal IQ is obtained from the five nonverbal subtests and can be used for assessing individuals with communication disorders, hearing impairments or deafness, ASD, specific learning disabilities, limited English-language proficiency, or traumatic brain injury. The Verbal IQ is obtained from the five verbal subtests and can be used for special cases of orthopedic or visual impairment. As part of hypothesis testing for Hypotheses 2 and 3 the present study used the Full Scale IQ and the Verbal IQ.

The internal reliability coefficients for the SB5 are calculated for each of the 10 subtests, the four IQ scores (Full Scale, Abbreviated Battery, Nonverbal, and Verbal), and the five factor index scores. Reliability coefficients for the IQ scores were computed using the formula for a reliability of a sum of multiple tests. For the Full Scale IQ the coefficients were high (.97 to .98). For the Abbreviated Battery IQ, which contains only two subtests, coefficients were excellent (average of .91). In comparison with other measures of cognitive functioning, correlations between the measures were substantial, ranging from .84 to .89.

The abilities measured by the SB5 are known to be relatively stable over time, therefore, they are expected to have good test-retest reliability. However, because of environmental variables, such as examinee mood or noise and distractions, test-retest reliability is not expected to be as high as the internal-consistency reliability coefficients presented above. Test-retest reliability for children aged two to five was based on a sample of 96 children. For the Full Scale IQ the corrected correlation (corrected using the variability correction of Cohen and Cohen (1983; as cited by Roid, 2003) in order to generalize the results to populations of all possible examinees) was .95. For the Abbreviated Battery IQ the corrected correlation was .87. Test-retest reliability for children between six and 20 years of age was based on a sample of 87 individuals. For the Full Scale IQ the corrected correlation was .93. For the Abbreviated Battery IQ the corrected correlation was .84. Compared to other measures of cognitive functioning, scores on the SB5 appear to be stable over time and are less affected by practice effects than other measures.

Interscorer agreement on the SB5 was calculated by two trained examiners who rescored the Record Forms for 120 protocols, approximately 40 of which had scores of 0, 40 had scores of 1, and 40 had scores of 2. Three correlations were obtained for each testlet: one between the original examiner and new examiner A, one between the original examiner and new examiner B, and one between new examiner A and new examiner B. Interscorer agreement correlations ranged from .74 to .97 with an overall median of .90, which shows high reliability and is comparable to other cognitive measures.

Content-related validity for the SB5 is based on professional judgement, the coverage of important constructs, and empirical item analyses (Kamphaus, 1993, as cited by Roid, 2003). During the test development phase of the SB5 numerous researchers and examiners were consulted. Among the groups consulted were an Advisory Panel that met on three occasions, hundreds of professional examiners who reviewed every item of the Tryout Edition, and reviewers representing various gender, racial/ethnic, and religious groups. All items of the SB5 were also rated for their consistency with items from previous Stanford-Binet editions to ensure that they measured the complex intellectual functions they were designed to assess. The SB5 was designed following the Cattell-Horn-Carroll (CHC) theory of intellectual abilities. As such, the assessment of content validity was also based on the extent to which the test covered the important constructs of the CHC model (fluid reasoning, knowledge, quantitative reasoning, visual-spatial processing, and working memory). All analyses converged to show consistent evidence of model-data-fit and content relevance. Finally, empirical item analysis of the criterion-related validity of the SB5 was achieved by comparing the SB5 with earlier versions (e.g., the SB-IV) and by examining the score profiles of individuals with existing diagnoses (e.g., gifted, intellectual disability, developmental delay, ASD, English-language learners, speech-language delays, learning disabilities, attention-deficit hyperactivity disorders, serious emotional disorders, and orthopedic or motor delays).

The construct validity of the SB5, that is, the extent to which the test measures what it is intended to measure, is based on the accumulation of evidence from numerous studies either supporting or refuting the relationship between specific test scores and the constructs they are intended to measure. In terms of age trends, when compared to the Woodcock-Johnson III Tests of Cognitive Abilities (WJ III) the SB5 appears to have good construct validity for its factor index scores. In addition, the SB5 is consistent with age changes in fluid and crystallized intelligence as reported by Horn (1970; 1985; as cited by Roid, 2003). Intercorrelations between subtest, factor index, and IQ scores support the general construct validity of the SB5. When compared with the SB IV (the preceding edition to the SB5) and the Wechsler scales of cognitive functioning, the SB5 is a strong measure of *g*, that is, of a general factor of cognitive ability. The author states that “the strength of the SB5 in measuring general ability is probably due to inclusion of items that are complex cognitively, including memory items that emphasize transformation of stored information (working memory)” (Roid, 2003).

Strengths and Difficulties Questionnaire, Extended Version (SDQ; Goodman, 2005). The SDQ is a 25-item behavioural screening questionnaire that is applicable for children and youth between the ages of 3 and 16 and is available in 40 different languages. There are five scales, with five questions each: emotional symptoms, conduct problems, hyperactivity and inattention, peer problems, and prosocial behaviour. Response choices are made on a three-point Likert scale (1 = not true, 2 = somewhat true, 3 = certainly true). The first four scales are summed to generate a Total

Difficulties score and individual scale scores are obtained by summing the five items on each scale. The SDQ is available in a parent, teacher, and youth self-report version, all of which are nearly identical except for the wording used (Goodman, 2001). An extended version includes an impact supplement that asks whether the child has a problem and, if so, further queries the level of distress caused by the problem, the social impact and burden of the problem, and how long the problem has been present (Goodman, 1999). The current study used the extended parent-report American English version of the SDQ to assess child function. The Total Difficulties score was used as an overall measure of child functional difficulties as part of hypothesis testing for Hypothesis 1. The emotional symptoms, conduct problems, hyperactivity and inattention, and peer problems scales were used as part of hypothesis testing for Hypothesis 2.

The SDQ was developed because there was a perceived need for a child behavioural screening questionnaire that was shorter and less time-consuming to complete than existing measures (such as Achenbach’s Child Behavior Checklist) and was more up to date than other frequently used measures such as the Rutter questionnaires (Goodman, 1997). Therefore, development criteria for the SDQ were that all items fit on one page; it be applicable for 4- to 16-year-olds; it exist in very similar versions for parents, teachers, and youth; it should query not only difficulties but also child strengths; and based on factor analysis conducted on an extended version of the Rutter questionnaires that identified a five-factor structure, the SDQ should map onto the same five dimensions, with an equal number of questions assigned to each factor (Goodman, 1997).

The SDQ has undergone extensive validation testing (for a complete list, please see http://www.sdqinfo.org/). For instance, parents and teachers of 403 children who were between the ages of four and 16 were recruited through one of two psychiatric clinics or a hospital-based dental clinic (Goodman, 1997). Participants completed both the SDQ and a Rutter questionnaire. Goodman (1997) reports that both the SDQ and the Rutter questionnaire were able to distinguish between the psychiatric sample and the dental clinic sample, as demonstrated by the nearly perfectly overlapping receiver operating characteristic (ROC) curves of the two measures. For both the SDQ and Rutter parent reports, the area under the curve was .87 (95% confidence interval = .83 - .91) while for the SDQ teacher report the area under the curve was .85 (95% confidence interval = .78 - .93) and for the Rutter teacher report the area under the curve was .84 (95% confidence interval = .76 - .93). Furthermore, parent-teacher correlations on the conduct problems, emotional symptoms, and hyperactivity scales were not significantly different between the SDQ and Rutter questionnaire. The SDQ peer problems and prosocial scales were not compared with the Rutter questionnaire as they have no equivalent scales on the Rutter questionnaire. A notable difference was found between the parent-teacher correlations on the SDQ Total Difficulties score ($r = .62$) and on the Rutter Total Deviance score ($r = .52$); the parent-teacher correlation was significantly higher on the SDQ than on the Rutter questionnaire (χ^2 (1) = 5.90, $p < .02$), suggesting that the SDQ parent and teacher versions are more comparable than the parent and teacher versions of the Rutter questionnaire. Goodman concludes that given the established reliability and validity of the Rutter questionnaires, the strong relationship between the SDQ and the Rutter questionnaire in the current study supports the concurrent validity of the SDQ.

In another study, Goodman and Scott (1999) compared the SDQ with one of the most commonly used tools for assessing childhood behaviour difficulties, the Child Behavior Checklist (CBCL). There are several noteworthy differences between the SDQ and CBCL. First, the SDQ is considerably shorter, with its 25 questions to the CBCL’s 118, making the SDQ much less time consuming to complete. Second, the authors report that item selection for the SDQ was based both on factor analysis (as mentioned above) and on DSM-IV and ICD-10 classifications of childhood psychopathology. Thus, all items on the SDQ are conceptually linked with current diagnostic criteria. The CBCL, on the other hand, was not developed to reflect such classifications and therefore, many scale items have no conceptual link to the childhood disorders they are intended to measure. Finally, while the CBCL psychopathology scale items are all negatively worded, the SDQ includes both positively and negatively worded questions, with the objective of making them more acceptable to respondents (Goodman & Scott, 1999). Nevertheless, Goodman and Scott hypothesized that the SDQ and CBCL should correlate highly, given that the SDQ and Rutter questionnaires were shown to correlate and that the Rutter questionnaires and CBCL have also been shown to have strong correlations. In their study, Goodman and Scott recruited mothers of 132 children who were between the ages of four and seven. As in Goodman (1997), participants were recruited from either psychiatric clinics or a dental clinic, in order to examine the sensitivity and specificity of the measures in terms of distinguishing between clinical and non-clinical populations (Goodman & Scott, 1999). The results showed that both the SDQ and CBCL distinguished between the psychiatric and dental samples, with no significant differences found between their ROC curves. All scales on the SDQ showed significant correlations with comparable scales on the CBCL and ranged from .87 on the total score through .59 on the social/peer scale. In addition, Goodman and Scott asked mothers in the dental clinic sample which questionnaire they preferred. Significantly more mothers preferred the SDQ over the CBCL (sign test, $z = 2.25$, $p < .025$). The SDQ therefore appears to perform equally to the CBCL in terms of identifying clinically significant levels of childhood behaviour problems and it is the measure preferred by those mothers surveyed.

In order to examine the reliability and validity of the SDQ with a larger, more representative sample, Goodman (2001) used data from the 1999 UK Office for National Statistics survey of 5- to 15-year-olds. The sample included parents of 9,998 children and youth. Completed teacher questionnaires were obtained for 7,313 of the children and youth. Of the 9,998 children and youth, 3,983 youth aged 11-15 also completed self-report questionnaires. The results from all three groups of respondents supported the previously identified five-factor structure. In terms of cross-scale correlations, the magnitudes of the internalizing-externalizing correlations were half the size of the externalizing-externalizing correlations, supporting the assumption that the internalizing and externalizing scales measure different constructs. Interrater correlations on the SDQ for this UK sample were compared with published meta-analytic data on the interrater correlations for the CBCL, and were found to be higher, suggesting good interrater agreement. The internal consistency of the SDQ was found to be satisfactory; Cronbach alpha coefficients had a mean of .73

and the Total Difficulties and Total Impact scores all had Cronbach alpha coefficients of at least .80. Test-retest reliability was assessed after a four to six month interval and was found to be .62. The author notes that this is likely to be the lower bound of retest reliability given that the time interval was longer than that typically used for test-retest assessments. In particular, given the content of the SDQ items, it is possible that actual changes may have occurred in the four to six month interval, which would then have impacted the scores. Goodman states that it is expected that with a smaller time interval, the test-retest reliability of the SDQ would be higher. Overall, the SDQ has been shown to have good reliability and validity as a short measure of childhood behaviour difficulties.

Supports and Services Questionnaire (SSQ; Summers et al., 2005). The SSQ was used to assess the type and frequency of services parents believe they and their children need and the extent to which those needs are being met. The SSQ is a list, rather than a scale, and as such psychometric properties of the measure have not been established (Email correspondence between D. McCauley & J. A. Summers, October 20, 2008). See the Appendix C for items.

Vineland Adaptive Behavior Scales-II, Survey Interview Form (Vineland-II; Sparrow, Cicchetti, & Balla, 2005). The Vineland-II was used to assess child adaptive functioning. The Vineland-II is a semi-structured survey interview conducted with parents or caregivers that assesses adaptive functioning in individuals between birth and 90 years of age (Sparrow, et al., 2005). The Vineland-II is composed of four domains: Communication, which is divided into receptive, expressive, and written communication; Daily Living Skills, which includes personal, domestic, and community activities; Socialization, which examines interpersonal relationships, play and leisure time activities, and coping skills; and Motor Skills, which is broken down into fine and gross motor abilities. These four domains make up the Adaptive Behavior Composite Score. The Vineland-II also includes a Maladaptive Behvior Index, made up of the Externalizing Behaviors and the Internalizing Behaviors scales (Sparrow et al., 2005). The present study used the Adaptive Behavior Composite to assess adaptive behaviour as part of hypothesis testing for Hypotheses 2 and 3. The Communication, Daily Living Skills, and Motor Skills domains as well as the Externalizing and Internalizing Behaviors scales were used as part of hypothesis testing for Hypothesis 2.

For the purpose of the present study, the interviewer used her clinical judgement regarding the appropriate start point for the interview. In some cases a start point one year below the child's chronological age was used and the interviewer worked backwards or forwards depending on responses provided by the parents. In other cases the interviewer used the start point appropriate for the child’s age and again worked backwards or forwards depending on the responses provided by the parents. The Vineland-II has a basal and a ceiling requirement of four. Therefore, when necessary, the interviewer worked backwards until a basal of four consecutive scores of two was attained. The interviewer stopped administering subtest items when a ceiling of four consecutive zeros was reached. The Vineland-II uses standard scores and has a mean of 100 and a standard deviation of 15. The Adaptive Behavior Composite has a maximum range of 20 to 160, that is, from five standard deviations below the mean to four standard deviations above the mean. Standard scores between 86 and 114 are considered Adequate, scores of 71 to 85 are considered Moderately Low, scores below 70 are considered Low, and scores between 115 and 129 or of 130 and higher are considered Moderately High and High, respectively (Sparrow et al., 2005). Using a sample of parents or caregivers (*n* = 112) of individuals with intellectual disability (ID), Sparrow et al. (2005) found that 71.1% of children aged six to 18 with mild ID (IQ range of 50 to 70) scored at or below a standard score of 70 on the Vineland-II. Within the same sample, 87.1% of children between six and 18 years of age with moderate ID (IQ range 35 to 49) scored at or below standard scores of 70. Finally, Sparrow et al. (2005) looked at children between six and 18 years of age who had severe to profound ID (IQ under 34) and found that 100% of those children scored at or below a standard score of 70.

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

Data analysis. The current investigation used structural equation modeling (SEM) to test the hypothesized model in Goal 1. All SEM analyses were conducted with version 3.0.2 of the R system for statistical computing (R Development Core Team, 2012), using the R package lavaan 0.5-16, which stands for latent variable analysis (Roseel, 2012). The measurement model was tested for model fit using the comparative fit index (CFI), the Tucker-Lewis index (TLI), the root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR). Following Byrne (2008), the cut-off used for the CFI was > .95. In addition to the CFI, the TLI was used as it has been found to be relatively independent of sample size (Marsh, Balla, & McDonald, 1988), although Hu and Bentler (1999) caution that with cut-off values >.95 the TLI has a slight tendency to over-reject true population models when sample sizes are small ($n \leq 250$), thus TLI values between .90 and .95 were considered acceptable for the current study (Hu & Bentler, 1999). The current analysis considered RMSEA values between .05 and .08 to indicate reasonable model fit, while SRMR values <.05 were chosen to indicate a well-fitting model (Byrne, 2008). In order to determine the extent to which the model accounted for parents' reports of their children's well-being, standardized estimates of the paths as well as the overall R^2 value were reported.

Hypothesis two (from Goal 2) was tested using IBM SPSS Statistics, Version 20. In order to facilitate comparison between AMC-26 and the SB5 and Vineland-II, factor analysis was performed to determine the factor structure of AMC-26. Reliability of AMC-26 was assessed using the complete sample from the larger study by calculating Cronbach's alpha for each of the factors identified in the factor analysis. Validity was assessed through Pearson correlations with relevant domains of the SB5 and Vineland-II and also through regression analysis with total scores on the CES-D.

Hypothesis three (from Goal 2) was tested with a series of multiple regression analyses, using IBM SPSS Statistics, Version 20. In order for a test of mediation to be justified, consistent significant relationships must be demonstrated to exist between the predictor and the outcome, between the predictor and the mediator, and between the mediator and the outcome. These significant relationships were hypothesized to exist for the present sample. The relationship between objectively assessed child functioning and parent perceptions of child well-being was thus hypothesized to be explained by the addition of the mediator “parent perceptions of child functioning,” as it was expected that parent perceptions of their children’s strengths and limitations influence how parents perceive the well-being of their children.

The following procedure applies to both the hypothesized mediated relationship between child cognitive functioning and well-being and the hypothesized mediated relationship between child adaptive functioning and well-being. There are four steps involved in testing a mediating relationship, as outlined by Kenny and his colleagues (Baron & Kenny, 1986; Kenny, Kashy, & Bolger, 1998; Judd & Kenny, 1981) and synthesized by Frazier, Tix, and Barron (2004). First, a significant relationship must be identified between the independent and the dependent variables (Path c in Figure 2). Second, there must also be a significant relationship between the independent variable and the hypothesized mediator (Path a in Figure 2). Third, the mediator must be significantly related to the dependent variable (Path b in Figure 2). Finally, the strength of the relationship between the independent variable and the dependent variable must be significantly reduced when the mediator is added to the model (Path c’ in Figure 2). In order to test the significance of the mediated effect, the significance of the products of Paths a and b were tested, according to the method described by Kenny et al. (1998) that involves dividing the product of Paths a and b by a standard error term: square root of $((b^2 * sa^2) + (a^2 * sb^2) + (sa^2 * sb^2))$, where a and b are the unstandardized regression coefficients and sa and sb are their standard errors. This equation yields a *z* score of the mediated effect. If the *z* score is greater than 1.96, the effect is significant at the .05 level.

Chapter 4: Results

Exploratory Data Analysis

Full sample. Using IBM SPSS Statistics, Version 20, the normality of the data was assessed both by calculating the skewness and kurtosis and by plotting Normal P-P and Q-Q plots for each variable used in the present study. The assumption of normality was met as all skewness and kurtosis values fell below +/- 1.96 and examination of the P-P and Q-Q plots revealed that all cases lined up along the diagonal. To further assess normality, histograms were generated using version 3.0.2 of the R system for statistical computing. Examination of the histograms revealed possible deviations from normality for some variables. Density smoothing was run on each of these possibly problematic variables, effectively correcting the effects of the data binning that was done to generate the histograms. The linearity of the data was assessed using R system for statistical computing. First, a bivariate scatter matrix of all variables used in the SEM analysis was plotted. Inspection of the scatter matrix showed that the data was roughly linear. In order to examine the linearity of the relationships further, and to identify possible outliers, 3D rotatable scatter plots were generated for each combination of variables (e.g., the amount that child support needs were met on the SSQ, the number of identified functional concerns on AMC-26, and the Being domain of the QLCDD). Two outlying cases were automatically excluded from the SEM by the R program as each was missing a score on the outcome measure. The remaining outliers were identified. Each individual outlier was removed in turn and relevant analyses (either the SEM or the regression analysis with AMC-26 and the CES-D) were re-run. None of the outliers was found to be leveraging the results, thus no cases were removed from the final SEM analysis or from the regression analysis tested in Hypothesis 3. Therefore, it was concluded that the results obtained from the analyses that were conducted using the full sample were robust.

Subsample. In order to investigate possible confounds due to background variables (e.g., parent marital status, family income, parent education, rural or urban community type, child age, and child sex), independent samples *T* tests were conducted for each relevant variable. The following group differences were identified: Parents who reported being married or in a common law relationship gave higher CAPE Overall Diversity scores for their children; Parents who had completed a university degree reported higher scores for their children on the Vineland-II Adaptive Behavior Composite; and Parents of girls reported higher scores on the Belonging and Becoming domains of the QLCDD and higher scores on the Overall Diversity scale of the CAPE. To control for these background variables, each was included as a categorical predictor in the relevant regression analyses. Neither parent marital status nor parent education had a significant effect on the results, thus neither was included in the final analyses. Child sex was found to have some significant effects on the results, and was therefore included in the final analyses.

Comparison analyses were run between the subsample and full sample in order to assess whether the samples differed in terms of family demographic characteristics or the relevant study constructs. Independent samples *t*-tests revealed no significant differences on the variable of caregiver age, or on mean scores for AMC-26, SDQ, QLCDD, and CES-D. The *t*-test requirement of a minimum of five cases per condition was not met for the following family demographic characteristics: marital status, parent education, and family income. Therefore, chi-square tests of independence were used to assess possible sample differences on these characteristics. No significant differences were found. Therefore, the subsample and full sample were deemed to be equivalent and no controls were necessary in subsequent data analyses.

As with the full sample, normality of the subsample data was assessed using IBM SPSS Statistics, Version 20 by calculating the skewness and kurtosis and by plotting the residuals and Normal P-P and Q-Q plots for each variable used in Hypotheses 2 and 3. All skewness and kurtosis values fell below +/- 1.96 and examination of the P-P and Q-Q plots revealed that all cases lined up along the diagonal, suggesting a normal distribution of the data. The residuals were determined to be normally distributed, given the even dispersion of cases above and below the fit line.

Histograms were generated for each variable using SPSS, with a few of the resultant graphs appearing to show some deviations from normality. As SPSS is known to bin data differently than some other statistical packages (L. Ainsworth, personal communication, July 22, 2014), histograms were next generated using the R program. The R-generated histograms binned the data better than SPSS, with distributions resembling a normal curve. Density smoothing applied to the data resulted in an even closer approximation to normality for all variables.

Linearity of the subsample data was assessed using version 3.0.2 of the R system for statistical computing. A bivariate scatter matrix of all variables used in the subsample analyses was plotted, providing a rough overview of the sample data. Initial examination of the scatter matrix showed likely deviation from linearity for the relationship between the Strengths and Difficulties Questionnaire and both the Full Scale IQ and Adaptive Behavior Composite predictors. As with the full sample, 3D rotatable scatter plots were generated next for each combination of variables, in order to examine the linearity of the data in more detail and identify possible outliers. The 3D rotatable plots showed definite deviations from linearity for the interaction between the Strengths and Difficulties Questionnaire and the two child functioning predictors. Therefore, the assumption of linearity was violated for this combination of variables, and it was determined that the Strengths and Difficulties Questionnaire should not be included in mediation analyses for Hypothesis 3. The 3D rotatable scatter plots facilitated identification of possible outliers in the subsample. Each individual outlier was subsequently removed from the data set and relevant analyses (for Hypotheses 2 and 3) were re-run. One case was found to be a significant outlier in analyses involving the Belonging domain of the QLCDD. Removal of this participant had a leveraging effect on one interaction: when Full Scale IQ was the indicator and the Belonging domain of the QLCDD was the outcome variable, and when child sex was not controlled for, removal of this participant produced a non-significant relationship between the predictor and the outcome. Removal of this participant from the data set had no effect on any other analyses, and was therefore only removed for the regression of Full Scale IQ on the Belonging domain of the QLCDD. The resulting data set met all assumptions and it was therefore concluded that the edited subsample data set would yield robust results.

Goal 1 (Hypothesis 1)

There were 234 participants available for use in the SEM analysis. Contrary to the hypothesized model, child age was not a significant predictor of child well-being and family socioeconomic status (SES) was not a significant predictor of support needs being met. Therefore, child age was removed from the model as was SES. Following the exploratory analyses examining demographic group differences in the subsample that suggested a possible effect of child sex, child sex was added into the SEM as a direct predictor of child well-being. However, child sex was not a significant predictor and its addition to the model did not improve model fit. Therefore, child sex was removed from the final model. The revised model was found to converge normally following 80 iterations and the factor structure of the revised model was supported. Each of the predictor variables loaded significantly on the overall outcome variable of well-being (standardized loadings: supports and services = -.52, function = -.17). Higher ratings of unmet support and service needs correlated negatively with child well-being, with parents who reported that more of their children's and families' service needs were unmet reporting lower well-being for their children with NDD. Parent perceptions of child functional difficulties also correlated negatively with child well-being; parents who reported more concerns about their children's functioning and reported that their children experienced more behavioural and emotional difficulties reported lower levels of child well-being. As predicted, there was a significant positive relationship between child function and supports and services. Testing the steps in a mediation analysis revealed that in line with the hypothesis, supports and services loaded significantly on function (standardized loading = .42), suggesting an indirect relationship between child function and child well-being. That is, supports and services served to mediate the relationship between child function and child well-being. Parent perceptions of their children's functional difficulties were differentially related to their children's well-being, depending on their perceptions of the adequacy of the supports and services their child and family received. Examination of the fit indexes revealed that the model fit the data reasonably well (CFI = .98; TLI = .95; RMSEA = .08, 90% CI: .05 - .12; SRMR = .03) and explained 38% of the variance in parent reported child well-being (see Figure 3).

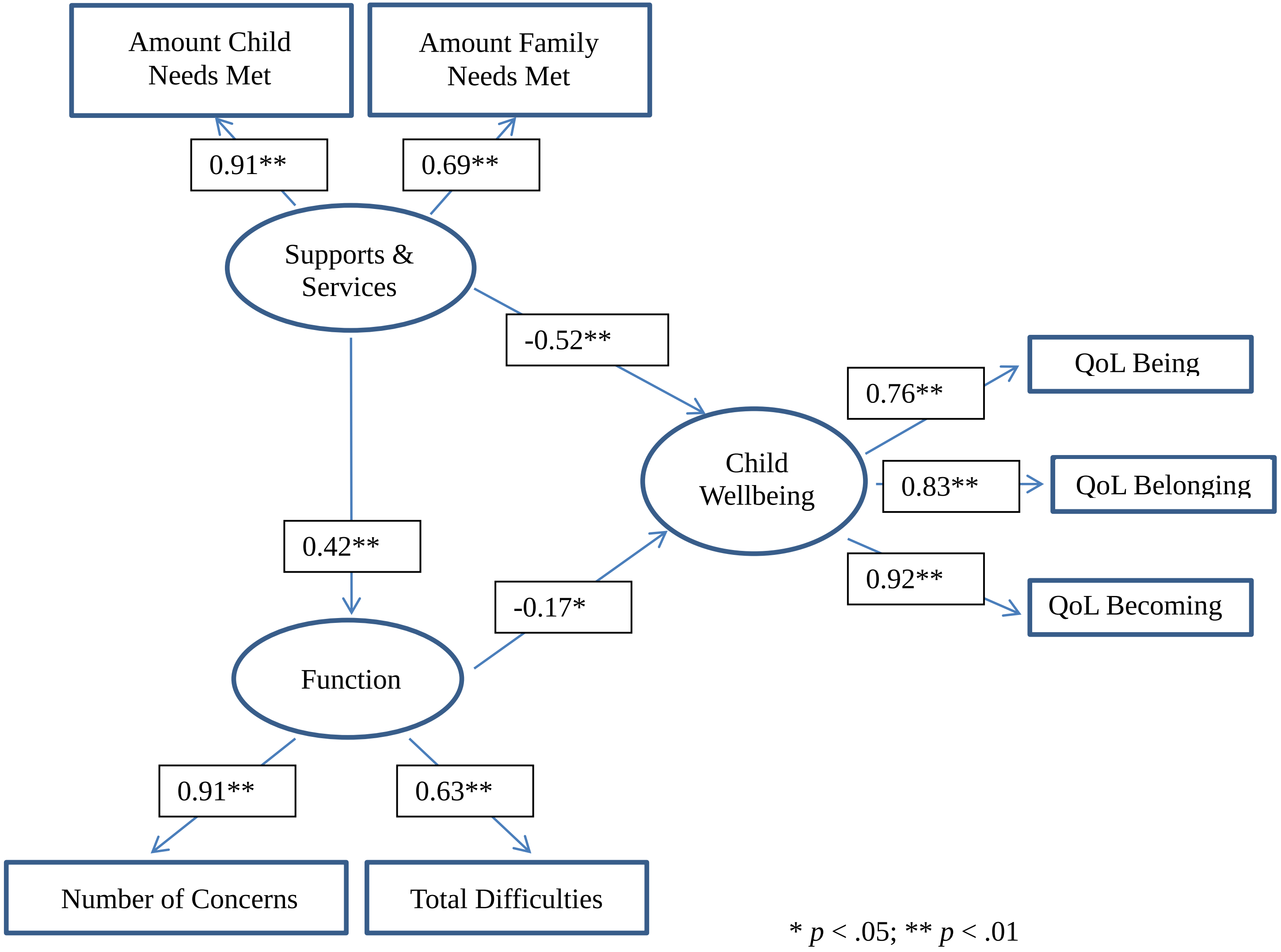

Figure 3. Structural model explaining parent perceptions of child well-being.

Goal 2

Hypothesis 2. It was hypothesized that AMC-26 is a valid measure of parent-reported child function. Specifically, it was hypothesized that the scale items and domains of AMC-26 would show good internal consistency. It was also hypothesized that the AMC-26 domains would correlate with related domains on existing standardized measures of child function. Finally, it was hypothesized that scores on AMC-26 would correlate with parent depressive symptoms.

Preliminary data analysis. In order to determine which scale items on AMC-26 should be used for reliability and validity analyses, factor analysis was performed on the 26 scale items. A five-component structure was supported (KMO = .81, p < .001), accounting for 45.96% of the variance. The following labels were assigned to the factors: Cognitive and Communication Concerns (comprises six items); Activities of Daily Living Concerns (comprises six items); Externalizing and Antisocial Behaviour Concerns (comprises seven items); Internalizing and Introverted Behaviour Concerns (comprises five items); and Body Functions (comprises two items).

Reliability. Following the factor analysis, it was hypothesized that items that loaded together and were therefore assumed to tap into related aspects of child function would correlate with one another. Factor 1, Cognitive and Communication Concerns, was found to have a high level of internal consistency (n = 260, Cronbach's alpha = .85). Factor 2, Activities of Daily Living Concerns, was also found to have a high level of internal consistency (n = 261, Cronbach's alpha = .81). Factor 3, Externalizing and Antisocial Behaviour Concerns, was found to have an acceptable level of internal consistency (n = 259, Cronbach's alpha = .77). Similarly, Factor 4, Internalizing and Introverted Behaviour Concerns, was found to have an acceptable level of internal consistency (n = 258, Cronbach's alpha = .74). Factor 5, Body Functions, was found to have a modest level of internal consistency (n = 261, Cronbach's alpha = .59). Finally, the complete set of 26 items was analyzed and was found to have a high level of internal consistency (n = 256, Cronbach's alpha = .84).

Validity. As a measure of function, derived from existing scales of child function and from developmental theory, the subdomains of AMC-26 (as determined by the factor analysis) were hypothesized to correlate with relevant subdomains on a measure of child cognitive function (SB5), child adaptive function (Vineland-II), and child behaviour problems (SDQ). As predicted, Factor 1 was found to have a significant negative correlation with Verbal IQ ($n = 49$, $r = -.66$, $p < .01$) and with Nonverbal IQ ($n = 48$, $r = -.50$, $p < .01$) on the SB5, and with the Communication Domain ($n = 49$, $r = -.66$, $p < .01$) on the Vineland-II. In line with the hypotheses, Factor 2 was found to have a significant negative relationship with the Daily Living Domain ($n = 49$, $r = -.49$, $p < .01$) and the Motor Domain ($n = 49$, $r = -.49$, $p < .01$) of the Vineland-II. Factor 3 was found to have significant positive correlations with the Externalizing Behavior score on the Vineland-II ($n = 49$, $r = .69$, $p < .01$), with the Conduct Problems scale of the SDQ ($n = 262$, $r = .54$, $p < .01$), and with the Hyperactivity and Inattention scale of the SDQ ($n = 260$, $r = .56$, $p < .01$), each of which supported the hypotheses. Factor 4 was found to have a significant positive relationship with the Internalizing Behavior score on the Vineland-II ($n = 49$, $r = .37$, $p < .01$) and with the Emotional Symptoms scale of the SDQ ($n = 262$, $r = .59$, $p < .01$). Factor 4 was also hypothesized to correlate with measures of social skills. In line with this hypothesis, Factor 4 was found to have a significant positive correlation with the Peer Problems scale of the SDQ ($n = 260$, $r = .35$, $p < .01$), although contrary to predictions, the correlation between Factor 4 and the Socialization Domain of the Vineland-II was not significant (see Table 4). No comparisons were made for Factor 5 as there were no appropriate counterparts in the comparison measures. Finally, the AMC-26 total number of identified concerns score was compared with the Full Scale IQ on the SB5 and with the Adaptive Behavior Composite score on the Vineland-II. As predicted, AMC-26 was found to negatively correlate with Full Scale IQ ($n = 48$, $r = -.43$, $p < .01$) and with the Adaptive Behavior Composite ($n = 49$, $r = -.66$, $p < .01$). Please see Table 4 for details.

It was hypothesized that greater child complexity, as assessed by a greater number of endorsed functional concerns on AMC-26, would serve as an indicator of parent depressive symptoms as measured by the CES-D. A simple linear regression was performed using total parent depressive symptoms as the outcome variable and total number of child functional concerns as the predictor variable (*n* = 251). The model was significant and explained 24% of the variance in parent depressive symptoms ($R^2 = .059$, $F(1, 251) = 15.74$, $p < .001$).

Table 4

Inter-Measure Correlations for Related Subdomains

	n	*r*
AMC Factor 1 : Cognitive/Communication		
Verbal IQ (SB5)	49	-.66**
Nonverbal IQ (SB5)	48	-.50**
Communication Domain (VABS-II)	49	-.66**
AMC Factor 2: Activities of Daily Living		
Daily Living Domain (VABS-II)	49	-.49**
Motor Domain (VABS-II)	49	-.49**
AMC Factor 3: Externalizing and Antisocial Behaviour		
Externalizing Behavior score (VABS-II)	49	.69**
Conduct Problems score (SDQ)	262	.54**
Hyperactivity and Inattention score (SDQ)	260	.56**
AMC Factor 4: Internalizing and Introverted Behaviour		
Internalizing Behavior score (VABS-II)	49	.37**
Socialization Domain (VABS-II)	49	-.19
Emotional Symptoms score (SDQ)	262	.59**
Peer Problems score (SDQ)	260	.35**
AMC Full Scale		
Full Scale IQ (SB5)	48	-.43**
Adaptive Behavior Composite (VABS-II)	49	-.66**

Note. SB5 = Stanford-Binet Intelligence Scales, 5th Edition; VABS-II = Vineland Adaptive Behavior Scales-II, Survey Interview Form, Second Edition; SDQ = Strengths and Difficulties Questionnaire
** $p < .01$

Hypothesis 3. It was hypothesized that parents' perceptions of their children's functioning would mediate the relationship between children's functioning as assessed by standardized measures of cognitive and adaptive functioning and parent perceptions of their children's well-being. If parent perceptions of child functioning were found to act as a complete mediator, then the relationship between child cognitive function and child well-being would be zero after parent-reported functioning was added to the model. If parent perceptions of child functioning were found to act as a partial mediator, then the relationship between child cognitive functioning and child well-being would be significantly smaller when parent-reported child functioning was added to the model.

The exploratory data analysis revealed that the background variable of child sex had a significant effect on three well-being outcomes: the Belonging and Becoming domains of the QLCDD and the Overall Diversity score of the CAPE. Therefore, in order to control for possible confounds, child sex was included as a categorical predictor variable in the regression analyses with these three outcomes. Overall, the hypothesis that parent perceptions of child function mediate the relationship between child cognitive and adaptive function and child well-being was supported. When child cognitive function (as assessed by the SB5) was used as the predictor, parent-reported child function (as assessed by AMC-26) acted as a partial mediator for the outcome of child well-being, when well-being was measured by the three domains of the QLCDD. When child adaptive function (as assessed by the Vineland-II) was used as the predictor, parent-reported child function (as assessed by AMC-26) acted as a partial mediator for the outcome of child well-being, when well-being was measured by all three domains of the QLCDD (see Tables 5 and 6 for the mediator effects). Each of the significant indirect effects was tested using the method outlined above (Kenny et al., 1998) and all were found to be significant at the .05 level (z scores ranged from 2.48 to 3.30). Post hoc power analysis was conducted using G*Power. With a sample size of 48 participants and an effect size of .35 ($p < .05$), the critical F was 3.20. All significant results from the mediation analysis were compared against this F value and were found to exceed it. Therefore, the estimated power of the mediation analyses was .95.

Several hypothesized relationships were not supported. Contrary to expectations, when the CAPE Overall Diversity score was used as the outcome variable, parent perceptions of child function did not mediate the relationship between child cognitive or adaptive function and child well-being.

Table 5

Testing the Mediator Effects of Parent-Reported Child Function on the Relationship between Child Cognitive Function and Parent-Reported Child Well-Being

Mediation Steps Tested	B	SE B	95% CI	β
Outcome: QoL Being				
Testing Step 1 (Path c)				
Outcome: QoL Being				
Predictor: FSIQ	.05	.02	.01, .09	.37**
Testing Step 2 (Path a)				
Outcome: Parent-report of function				
Predictor: FSIQ	-.10	.03	-.16, -.04	-.43**
Testing Step 3 (Paths b and c’)				
Outcome: QoL Being				
Mediator: Parent-report of function	-.41	.08	-.57, -.25	-.62**
Predictor: FSIQ	.02	.02	-.02, .05	.11
Outcome: QoL Belonging				
Testing Step 1 (Path c)				
Outcome: QoL Belonging				
Predictor: FSIQ	.04	.02	-.00, .08	.28*
Predictor: Child sex	2.30	.96	.37, 4.24	.33*
Testing Step 2 (Path a)				
Outcome: Parent-report of function				
Predictor: FSIQ	-.09	.03	-.14, -.03	-.41**
Predictor: Child sex	-2.79	1.40	-5.61, .04	-.26*
Testing Step 3 (Paths b and c’)				
Outcome: QoL Belonging				
Mediator: Parent-report of function	-.25	.10	-.45, -.06	-.38*
Predictor: FSIQ	.02	.02	-.02, .06	.13
Predictor: Child sex	1.60	.94	-.30, 3.51	.23
Outcome: QoL Becoming				
Testing Step 1 (Path c)				
Outcome: QoL Becoming				
Predictor: FSIQ	.05	.02	.02, .09	.38**
Predictor: Child sex	2.09	.96	.15, 4.02	.29*
Testing Step 2 (Path a)				
Outcome: Parent-report of function				
Predictor: FSIQ	-.10	.03	-.16, -.04	-.44**
Predictor: Child sex	-3.14	1.44	-6.03, -.25	-.28*
Testing Step 3 (Paths b and c’)				
Outcome: QoL Becoming				
Mediator: Parent-report of function	-.40	.09	-.57, -.23	-.59**
Predictor: FSIQ	.02	.02	-.02, .06	.14
Predictor: Child sex	.97	.83	-.69, 2.64	.14
Outcome: CAPE Overall Diversity				
Testing Step 1 (Path c)				
Outcome: *CAPE Overall Diversity*				
Predictor: FSIQ	.17	.03	.11, .23	.59**
Predictor: Child sex	5.73	1.56	2.59, 8.86	.39**
Testing Step 2 (Path a)				
Outcome: Parent-report of function				
Predictor: FSIQ	-.10	.03	-.16, -.04	-.44**
Predictor: Child sex	-3.14	1.44	-6.03, -.25	-.28*
Testing Step 3 (Paths b and c’)				
Outcome: *CAPE Overall Diversity*				
Mediator: Parent-report of function	-.16	.16	-.48, .17	-.12
Predictor: FSIQ	.16	.04	.09, .23	.54**
Predictor: Child sex	5.24	1.64	1.94, 8.54	.36**

Note. CI = confidence interval; FSIQ = Full Scale IQ, SB5.

* $p < .05$; ** $p < .01$

Table 6

Testing the Mediator Effects of Parent-Reported Child Function on the Relationship between Child Adaptive Function and Parent-Reported Child Well-Being

Mediation Steps Tested	B	SE B	95% CI	β
Outcome: QoL Being				
Testing Step 1 (Path c)				
Outcome: QoL Being				
Predictor: ABC	.11	.03	.06, .17	.49**
Testing Step 2 (Path a)				
Outcome: Parent-report of function				
Predictor: ABC	-.24	.04	-.31, -.16	-.66**
Testing Step 3 (Paths b and c')				
Outcome: QoL Being				
Mediator: Parent-report of function	-.40	.10	-.59, -.20	-.61**
Predictor: ABC	.02	.03	-.05, .09	.09
Outcome: QoL Belonging				
Testing Step 1 (Path c)				
Outcome: QoL Belonging				
Predictor: ABC	.10	.03	.04, .17	.43**
Predictor: Child sex	1.98	.95	.06, 3.89	.26*
Testing Step 2 (Path a)				
Outcome: Parent-report of function				
Predictor: ABC	-.23	.04	-.31, -.15	-.64**
Predictor: Child sex	-1.79	.04	-4.24, .67	-.16
Testing Step 3 (Paths b and c')				
Outcome: QoL Belonging				
Mediator: Parent-report of function	-.26	.11	-.48, -.04	-.38*
Predictor: ABC	.05	.04	-.03, .12	.19
Predictor: Child sex	1.52	.93	-.36, 3.39	.20
Outcome: QoL Becoming				
Testing Step 1 (Path c)				
Outcome: QoL Becoming				
Predictor: ABC	.13	.03	.07, .18	.54**
Predictor: Child sex	1.46	.87	-.28, 3.20	.20
Testing Step 2 (Path a)				
Outcome: Parent-report of function				
Predictor: ABC	-.23	.04	-.31, -.15	-.64**
Predictor: Child sex	-1.79	.04	-4.24, .67	-.16
Testing Step 3 (Paths b and c')				
Outcome: QoL Becoming				
Mediator: Parent-report of function	-.34	.10	-.53, -.14	-.49**
Predictor: ABC	.06	.03	-.01, .12	.24
Predictor: Child sex	.92	.79	-.68, 2.51	.13
Outcome: CAPE Overall Diversity				
Testing Step 1 (Path c)				
Outcome: *CAPE Overall Diversity*				
Predictor: ABC	.27	.05	.17, .37	.57**
Predictor: Child sex	4.31	1.61	1.06, 7.56	.29**
Testing Step 2 (Path a)				
Outcome: Parent-report of function				
Predictor: ABC	-.23	.04	-.31, -.15	-.64**
Predictor: Child sex	-1.79	.04	-4.24, .67	-.16
Testing Step 3 (Paths b and c')				
Outcome: *CAPE Overall Diversity*				
Mediator: Parent-report of function	.04	.20	-.36, .43	.03
Predictor: ABC	.28	.07	.14, .42	.59**
Predictor: Child sex	4.37	1.67	1.01, 7.74	.30**

Note. CI = confidence interval; ABC = Adaptive Behavior Composite, Vineland-II.
* p < .05; ** p < .01

Chapter 5: Discussion

This study had two primary goals: to identify factors that influence parent perceptions of child well-being and to contribute to the research design of the larger Parenting Matters! study. The discussion will first address Goal 1 and its associated hypothesis. Next, Goal 2 and the research questions and hypotheses it sought to address will be discussed. Finally, the policy and practice implications of the study as a whole will be examined with reference to the Canadian context.

Goal 1 (Hypothesis 1)

The first goal was to examine factors that influence parent perceptions of child well-being. This goal was addressed by examining a model of child well-being in which formal supports and services for the child and family and parent perceptions of child functional difficulties were hypothesized to contribute to overall child well-being. Evidence for the hypothesized model was found, supporting the results of previous studies. Parents who reported that a greater number of their child’s and family’s service needs were met reported higher levels of well-being for their children. This finding is in line with the results of recent studies examining the relationship between supports and services and parent well-being (e.g., Benson, 2012; Burke & Hodapp, 2014; McConnell et al., 2010), and provides new information regarding the impact that services can have on well-being, not just for parents, but for children as well.

The hypothesized relationship between child functional difficulties and child well-being was also supported. Those parents who reported having fewer concerns about their children’s functioning also reported higher levels of well-being for their children. Studies of children with physical disabilities and medical conditions have demonstrated similar relationships (e.g., Law et al., 2004; McDonald et al., 2010; Payot & Barrington, 2011; Zwicker et al., 2012), and the results of the current study are an important addition to our understanding of the role of function in the well-being of children with a range of difficulties. In addition to the direct relationships between supports and services and child well-being and between child function and child well-being, the current study found support for an indirect pathway between function and well-being, with supports and services mediating the relationship. This means that the relationship between child function and well-being was explained by the extent to which child and family needs were met. When parents reported that their support needs were adequately met, their children's functional difficulties had a lower impact on parent perceptions of their children's overall well-being. This outcome is in line with ICF-CY guidelines that stipulate the importance of providing adequate supports in order to bridge the gap between children's functional limitations and their ability to participate in activities that are meaningful to them (WHO, 2002). Support for a mediated relationship between child function and child well-being, with supports and services acting as the mediator, also comes from a recent investigation with children with health conditions such as orthopaedic impairment, developmental delay, and speech-language disorder (Anaby et al., 2014) and from a systematic review of 19 studies examining the relationship between participation and quality of life for children with NDD (Dahan-Oliel et al., 2012).

Goal 2

A second goal of the current study was to contribute to the research design of the larger Parenting Matters! project. This goal was achieved by examining the reliability and validity of the AMC-26 tool and also by the direct assessment of a subsample of children using measures of cognitive and adaptive function.

Hypothesis 2. AMC-26 was hypothesized to be a valid measure of parent-reported child function. Evidence for the reliability and validity of the measure was obtained. The five-factor model was found to have a high degree of internal consistency, as evidenced by the obtained Cronbach's alphas. AMC-26 also showed good convergent validity when compared with existing validated measures of child function. Finally, the overall score on AMC-26 was found to be significantly related to caregiver distress. Therefore, this study provides evidence of the validity and reliability of AMC-26, supporting its use as both a clinical and research tool to assess child function and child health complexity.

AMC-26 can be used as a clinical tool to identify family priorities. Items on AMC-26 have high face validity, making them easy to understand by diverse users (e.g., parents, multidisciplinary clinicians, researchers). This means that AMC-26 can be used across disciplines and between service agencies to facilitate communication and to guide discussions with families. An area for further study is the use of AMC-26 as a screening tool in clinical settings. Given that respondents are asked to report on the number of concerns they have for their child, with appropriate service provision parent concerns would ideally decrease and these changes may be reflected in ratings on AMC-26. This possibility requires further testing as AMC-26's sensitivity to change has not yet been demonstrated. Therefore, the possible role of AMC-26 in intervention studies is an area for future research.

As a research tool AMC-26 holds much promise. The current study supported the use of AMC-26 as a measure of child function, by demonstrating strong correlations with existing measures of child function. AMC-26 offers many advantages over standardized measures of cognitive and adaptive function. First, AMC-26 is much faster to administer than measures of cognitive and adaptive function. Second, unlike measures of cognitive and adaptive function, users of AMC-26 do not require specialized training or qualifications. The use of a brief checklist like AMC-26 is therefore a more efficient tool for identifying functional concerns in the context of practice and research. AMC-26 can also be used in research as a tool to describe the sample, providing supplemental demographic information. Furthermore, the current study revealed significant positive correlations between higher levels of reported concerns on AMC-26 and caregiver psychological distress. Therefore, AMC-26 may be used as a tool for examining the role of child health complexity in overall family burden and caregiver well-being. Implications for further researcher regarding AMC-26 are expanded upon in a later section.

Hypothesis 3. It was hypothesized that parent perceptions of child function would mediate the relationship between child cognitive and adaptive function and child well-being. Overall, this hypothesis was supported. Parent perceptions of their children's functioning mediated the relationship between directly assessed child cognitive functioning and child well-being as reported by parents on a measure of quality of life. The same relationship was found for children's adaptive functioning. This suggests that, similar to what was found with the full sample, child function does impact well-being. However, it appears that it is parent *perceptions* of their children's functioning that influences well-being more than children's "actual" or measured functioning. An important consideration in the interpretation of the results from Goal 1 was whether or not parent reports of child function were correlated with more objectively assessed child function. The findings from the AMC-26 validation study supported the use of that measure as a measure of child function. In fact, parent reports on AMC-26 correlated significantly with observed results on the measures of cognitive and adaptive function. Yet, the AMC-26 validation study did not elucidate in what way the two might be correlated, and did not provide information on the relationship between perceived and observed function and child well-being. Clarifying the relationship between parent concerns about their children's functioning, children's directly measured functioning, and children's well-being is necessary in order to be able to effect change. The results of the mediation analysis conducted using the subsample suggest that we might be able to positively impact the relationship between child function and well-being by improving parent perceptions of their children's functioning, possibly through the provision of sufficient supports and services which may help to decrease parents' negative experience of their children's needs.

The notion of improving parent perceptions of their children's functioning falls well within the intended use of AMC-26 and is expected in the case of a mediated relationship, given that the mediator should be something that can be changed (Frazier, Tix, & Barron, 2004) such as individual beliefs (Baron & Kenny, 1986). Trute and his colleagues (Trute, Benzies, Worthington, Reddon, & Moore, 2010) proposed that positivity might act as a psychological coping resource for mothers of children recently diagnosed with a disability. Through phone interviews with a sample of mothers whose children were diagnosed with a disability within the previous three to 12 months and who were enrolled in Alberta's Family Support for Children with Disabilities (FSCD) program (n = 237 mothers), Trute et al. (2010) found that mothers with higher positive appraisals of the impact of having a child with a disability had better overall family adjustment. Similarly, in a mixed methods study that involved interviews and questionnaires completed with Taiwanese mothers of children with ASD, Lin, Orsmond, Coster, and Cohn (2011) found that mothers who used more problem-focused as opposed to emotion-focused coping reported lower levels of depressive and anxious symptoms. Likewise, Woodman and Hauser-Cram (2013) found that positive coping strategies were related to greater parenting efficacy and lower depressive symptoms in mothers of adolescents with developmental disabilities. Of note, both Trute et al. (2010) and Woodman and Hauser-Cram (2013) explored the notion that both positive and negative parent appraisals can be present at the same time, but that the use of more effective coping strategies can serve to mitigate the negative effects associated with parenting children with disabilities. Such findings may help to elucidate why some families do well, while others apparently do less well when faced with the challenge of raising a child with a disability. As part of a longitudinal study of families of children with disabilities in the province of Manitoba, Thompson, Hiebert-Murphy, and Trute (2012) found that for both mothers ($n = 97$) and fathers ($n = 61$), greater parent self-esteem was related to more positive family adjustment. These authors suggest that interventions targeted at improving parent self-esteem might therefore help to improve overall family adjustment to disability. McConnell, Savage, and Breitkreuz (2014) expand upon this notion and suggest that parental resilience to a child's disability may have more to do with access to adequate supports and services that contribute to effective coping rather than to parents' internal coping mechanisms. The theoretical rationale for the role of environmental supports in promoting the healthy development of children's interconnected systems is consistent with Bronfenbrenner's bioecological model (2001).

Parents of children with NDD play a central role in caring for their children throughout their lives; if they are to be able to fulfil the task of caregiver then they must be adequately supported (Hewitt, Agosta, Heller, Williams, & Reinke, 2012). In the context of the current study, parents who hold more positive perceptions about their children's functioning might be more resilient to the challenges of parenting, which then contributes to higher ratings of their children's well-being. The results of the SEM support McConnell et al.'s (2014) findings, suggesting that adequate supports and services contribute to more positive perceptions of child function, and consequently, to greater overall well-being. Therefore, when taken as a whole, the results from each of the three research questions point to specific areas that should be targeted by our systems of care that support children with NDD, in order to promote child well-being.

Policy Implications

This section outlines some of the policy implications of the current research study. There is growing consensus among researchers that the time is right to move from talking about change to implementing changes, and that policy makers must take note of the support needs of families caring for individuals with NDD (Garner et al., 2013; Hewitt et al., 2013; Lach et al., 2009). This section will examine the current public policy landscape with respect to NDD in the three provinces from which the clinical data for the present study was collected (Ontario, Alberta, and Quebec), note how these policy landscapes align with the present study, and then consider implications for broader national policy. Finally, recommendations generated by key stakeholders in the area of childhood disability will be presented and linked with the results of the present study.

Ontario. In Ontario, the most influential policy document pertaining to children and adults with developmental disabilities at the present time is *Inclusion and Opportunity: A New Path for Developmental Services in Ontario,* which was presented to the Ontario Legislature in July 2014 (Legislative Assembly of Ontario, 2014). This report was written by a Select Committee on Developmental Services, whose members span political parties and affiliations. *Inclusion and Opportunity* contains a set of recommendations for improving the lives of children and adults with developmental disabilities, several of which are relevant to the present study.

Two important areas of focus for *Inclusion and Opportunity* are the need for empirical data to support policy change, and the need for communication and coordination between government ministries. In its report, the Select Committee noted that both of these domains are lacking in Ontario: there is a current paucity of research related to services for people with NDD, and more importantly there is a lack of communication and coordination between government ministries providing services for individuals with NDD (Legislative Assembly of Ontario, 2014). The Select Committee found that there was an information gap with respect to both the demand for and provision of developmental services, and recommended that data be collected in both of these areas. The report recommended that ideally data would be collected annually on a province-wide scale. Areas of data collection relevant to the current study include determining the number of children with NDD residing in Ontario, the number of children with a dual diagnosis, the length of waitlists for services, and the number of individuals with NDD who are inappropriately housed (Legislative Assembly of Ontario, 2014). The importance of looking across ministries and organizations was also highlighted. The report noted that efforts are often highly siloed, with little communication between ministries, and sometimes even little collaboration between divisions within a single ministry. This kind of siloing can lead to misaligned initiatives which are collectively self-defeating, or duplication of efforts that are inefficient (Legislative Assembly of Ontario, 2014).

Furthermore, the Select Committee acknowledged that a truly person-centred framework must empower individuals and families to customize their service plans to meet their individual needs. The Select Committee referred to existing models of person-directed planning in British Columbia and in the United Kingdom, and presented further support for such a model from the United Nations Convention on the Rights of Persons with Disabilities. Importantly, the Select Committee identified some of the barriers that are currently limiting participation and inclusion, including access to affordable planning support (Legislative Assembly of Ontario, 2014).

The present study is highly aligned with *Inclusion and Opportunity*, and provides a solid evidence-based foundation to support several of its claims. For example, in line with the Select Committee’s recommendation that data be collected to determine the service needs of individuals with NDD, the present study provides empirical data regarding parent perceptions of the adequacy of the supports and services received by families and directly ties adequacy of supports and services to child well-being. Furthermore, one of the report's key messages is that a uniform approach to service provision is suboptimal. The present study supports this conclusion. The results of the current investigation suggest that when we look at supports and services and child function independently, both are strong predictors of child well-being. However, when we look at them together, we see that the role of function depends on the level of supports and services. That is, the level of support that families perceive they are receiving impacts the extent to which their children's functional difficulties are perceived to impact their well-being. Therefore, in line with *Inclusion and Opportunities'* recommendation that service provision should not be based on a one-size-fits-all model, the current study reinforces the importance of looking beyond a single indicator (such as function) and instead including environmental factors such as individual perceptions of support adequacy. The current study results suggest that policymakers should take *Inclusion and Opportunities'* recommendations seriously.

Alberta. Policy leaders in Alberta have been at the forefront of legislative change for individuals with NDD. A decade before Ontario's Select Committee report, the Alberta legislature passed the *Family Support for Children with Disabilities Act* (FSCD), signing into law provisions for child- and family-centred supports and services (Government of Alberta, 2013). Accompanying the FSCD Act is a comprehensive program and policy manual which is continually updated and amended, based on new empirical data and on the changing needs of Alberta's population (Government of Alberta, 2004). The FSCD Act was developed in consultation with parents of children with disabilities, community stakeholders, advocates, healthcare professionals, aboriginal representatives, and service providers.

Central to the FSCD Program is a family-centred approach, which recognizes that child and family well-being are promoted when supports and services are provided early and in a timely manner (Government of Alberta, 2004). Within this proactive framework, parent and family needs are accorded equal weight alongside child needs. Family support services covered by the FSCD program include information, referral, advocacy services, family and individual counselling, and family and respite support, all of which are based on the needs of the family (Government of

Alberta, 2004). Child-focused services are based on the needs of the child and span a wide range of supports and services including transportation and child care costs, behavioural/developmental interventions, specialized intervention services, and health-related supports.

Even though the FSCD Program falls under the mandate of the Ministry of Human Services, which is separate from the Ministry of Health, the FSCD Program explicitly includes provisions related to the medical health of children with disabilities. In this way, the FSCD Program is already engaging in the type of cross-ministerial collaboration recommended by Ontario's Select Committee. In fact, the Alberta Government has recognized the importance of cross-ministerial partnerships in supporting the complex needs of adults with dual diagnosis (i.e., developmental disabilities and mental health difficulties; Alberta Health Services, 2014a). Similarly, although primarily focused on adult services, a recent Complex Service Needs Newsletter from December 2014 includes information regarding children's mental health (Alberta Health Services, 2014b), suggesting possible avenues for increased collaboration.

The present study provides support for the family-centred model adopted by FSCD. The notion of supporting the whole family aligns with the results of the current study that showed that providing services to all family members has direct benefits for children with NDD. Furthermore, the FSCD program recognizes the importance of inter-ministerial collaboration. Although not directly related to the findings of the present study, it can be argued that providing comprehensive supports and services to all family members requires collaboration between the ministries responsible for providing health, education, and social services. FSCD's inclusion of parent-focused services such as counselling aligns with the findings presented in the literature review, showing significant associations between parent well-being and parenting capacity. Therefore, Alberta's FSCD model of service provision for families of children with NDD has many positive and evidence-based features, and might be used as an example by other provinces seeking to reform their service models.

Quebec. In Quebec, disability legislation has its roots in Bill 112, the *Loi visant à lutter contre la pauvreté et l'exclusion sociale* [An Act to combat poverty and social exclusion], unanimously assented to by the Quebec Legislature in December 2002 (Government of Québec, National Assembly, 2002). The Act's objective is:

> To guide the Government and Quebec society as a whole toward a process of planning and implementing actions to combat poverty, prevent its causes, reduce its effects on individuals and families, counter social exclusion and strive toward a poverty-free Quebec. (Government of Québec, National Assembly, 2002, p. 5)

This objective was addressed by the creation of a National Strategy to combat poverty and social exclusion that was directed by five principals: (a) preventing poverty and social exclusion by focusing on individual potential; (b) strengthening social and economic supports; (c) promoting access to employment; and (d) ensuring that at all levels of implementation there is consistent and coherent intervention. Within the National Strategy individuals with disabilities are recognized as being vulnerable to higher rates of poverty than able-bodied citizens, and so special consideration is given to ensuring that the implantation of the Act through the National Strategy accounts for these more vulnerable individuals (Government of Québec, National Assembly, 2002).

While the Act primarily addresses the needs of adults, the second five-year plan to emerge from the Act, entitled *Plan d'action gouvernemental pour la solidarité et l'inclusion sociale 2010-2015 : Le Québec mobilisé contre la pauvreté* [Government Action Plan for Solidarity and Social Inclusion 2010-2015: Québec's Combat Against Poverty], recognized the importance of supporting children and youth in order to adequately prepare them for entry into the adult workforce (Ministère de l'Emploi et de la Solidarité Sociale, 2010). In line with this strategic direction, provisions for children and youth with disabilities were made in the Ministère de l'Éducation, du Loisir et du Sport (2008) *Plan d'action pour soutenir la réussite des élèves handicapés ou en difficulté d'adaptation ou d'apprentissage* [Conditions for Greater Success - Action Plan to Promote Success for Students with Handicaps, Social Maladjustments or Learning Disabilities]. This Action

Plan for Students addresses many important components of Quebec's special education system for children with disabilities. However, although the Action Plan recommends increased collaboration between the ministère de l'Éducation, du Loisir et du Sport and the ministère de Santé et Services Sociaux, the extent of this collaboration appears limited primarily to the training of professionals and the provision of early intervention services for very young children (Ministère de l'Éducation, du Loisir et du Sport, 2008). Although Quebec seems to view itself as a socially progressive province in which individuals with disabilities are well supported, existing legislation has not yet focused specifically on the needs of children with disabilities beyond the education system.

The results of the current study suggest ways in which Quebec might strengthen its legislation to account for the particular needs of children with NDD and their families. For instance, application of Quebec's Bill 112 is made based on financial need and is therefore available only to those individuals who meet the financial eligibility requirements, regardless of level of functional impairment. The findings from the present study extend our understanding of the role of child function, suggesting that child function impacts the well-being of both parents as well as children. Therefore, it is imperative that disability legislation account for the large variability in functioning across individuals with NDD and that supports and services be tailored to meet different levels of need. One concrete implementation of the present research could be for Quebec to add child function to the eligibility criteria for certain supports and services so that decisions are not based solely on financial need.

National. The preceding discussion highlights not only the large variability in disability legislation between Canadian provinces but also the evident need for increased cross-ministerial collaboration within provinces, and at a more fine grained level, greater communication and collaboration between the various professionals working with children with NDD. Children spend much of their time in schools, yet without appropriate support, ministries of education may be unable to provide the level of service that children with NDD require in school. Collaboration between schools, healthcare centres, and social service agencies might facilitate the implementation of integrated services to meet the complex needs of children with NDD. School psychologists and family physicians are ideally situated to engage in such transdisciplinary collaboration (Ritzema, Sladeczek, Ghosh, Karagiannakis, & Manay-Quian, 2014). Unfortunately, this sort of communication rarely occurs.

Using national data from Statistics Canada, Mâsse, Miller, Shen, Schiariti, and Roxborough (2013) found that children with motor impairments and children with ASD had the lowest levels of participation in both supervised and unsupervised physical activity at school, when compared with children with other forms of NDD. Children with ASD and those with psychological impairments (primarily attention deficit-hyperactivity disorder) experienced the lowest levels of participation in educational activities, suggesting that there is insufficient support for children with these forms of NDD to participate fully in school-based activities. Similarly, Law, Petrenchik, King, and Hurley (2007) found that children with physical disabilities (including CP, spina bifida, acquired brain injury, developmental delay, and other central nervous system and musculoskeletal disabilities) faced more environmental barriers to accessing supports and services and in participating in activities both at school and in the community, compared to children without disabilities. In a qualitative case study of four students with fragile X syndrome in Australia, Baker and Donelly (2001) found that special education classes that were separate from regular classes served to isolate children both physically and socially from their peers. These authors found that academic goals often superseded social goals, with the result that schools did not have specific policies to address social inclusion. Yet, Baker and Donelly suggest that school-based policies might be necessary to shift both school and community views of disability. They note that if classroom- and community-level social skill building strategies are to work, the groundwork must be laid at the level of the school where positive peer interactions will provide the foundation for all other social relationships. Positive school interactions appear to have diffuse effects that can extend to the level of parent well-being (Burke & Hodapp, 2014). In a national study of mothers of children with disabilities conducted in the United States, Burke and Hodapp (2014) found that those mothers who reported more positive relationships with their children’s school also reported lower levels of stress, compared to mothers who had more negative parent-school relationships.

The extensive literature demonstrating a positive relationship between leisure participation and the well-being of children with NDD (e.g., Dahan-Oliel et al., 2012; Law, 2002) supports a multi-dimensional model of participation that includes the community environment, family factors, and child factors (e.g., Coster et al., 2012; King, Law, King, Rosenbaum, Kertoy, & Young, 2003). This literature furthermore suggests a mediating role of the environment in shaping children’s participation in leisure activities (e.g., Anaby et al., 2014), and the vast amount of work that has emerged since the publication of the ICF and ICF-CY provides direction for the sort of interventions that are needed in order to increase the participation of children with disabilities (e.g., Eriksson et al., 2007; King et al., 2003; Law, 2002).

In the context of this previous body of work, the results of the current study suggest that greater attention should be paid to the role of social inclusion in schools and to the relationship between schools and families. In the present study, the Children’s Assessment of Participation and Enjoyment (CAPE; King et al., 2004) was hypothesized to measure children’s well-being, given the empirical support for the relationship between participation and well-being. Yet, this hypothesis was not supported. There are several possible explanations for this result. The CAPE has not yet been demonstrated as a valid measure for use with children with NDD, therefore it is possible that it is inappropriate for use with this population. The CAPE asks specifically about children’s participation in activities outside of school instruction. Keeping in mind the discussion above, one possibility is that the school environment may play not only a key role, but the central role, in promoting the well-being of children with NDD through the inclusion of these children in both formal and informal recreation and leisure activities. By excluding these experiences, the CAPE may fail to tap into one of the most important environmental contributors to well-being for children with NDD. Another possibility is that the CAPE does not give sufficient weight to the quality of children’s engagement, focusing instead on the number of activities in which children participate.

Recent work by King and her colleagues (e.g., King, Rigby, & Batorowicz, 2013; King et al., 2014) suggests that measures such as the CAPE may lack explanatory power when it comes to uncovering the mechanisms by which environments promote or hinder participation. These authors recommend soliciting children's perceptions about the quality of their experiences, in order to capture the more specific environmental aspects of participation and enjoyment. Therefore, the CAPE may not be sensitive enough to the particular factors at play in the participation of children with NDD. Moreover, heeding calls for increased collaboration between healthcare and education (Ritzema et al., 2014) and implementing a unified cross-ministerial approach to service provision that bridges the gaps between the silos of care for children with NDD may provide additional insight into the quality of children's participation across settings.

Benefits evaluation. The present study has implications for the evaluation of publicly funded programs, a process sometimes referred to as program evaluation or benefits evaluation. This is because, as publicly funded institutions across Canada face increasing fiscal pressures, benefits evaluation will play an increasingly important role in deciding which programs receive funding.

To stress the importance of this point, it is worth examining some of these fiscal pressures in more detail. At the provincial level, for example, in 2012 the Commission on the Reform of Ontario's Public Services issued their report entitled *Public services for Ontarians: A path to sustainability and excellence* (Ontario Ministry of Finance, 2012), which is popularly referred to as the Drummond Report, in reference to the Commission Chair, Don Drummond. The Drummond Report proposed sweeping cuts to all manner of social services in the name of a balanced budget (Ontario Ministry of Finance, 2012). Although Ontario Premier Kathleen Wynne has instructed her Minister of Community and Social Services to "help adults with developmental disabilities and their families live as independently as possible" (Wynne, 2014), it remains to be seen exactly how this will pan out in practice, especially given the Liberal Government's commitment to implementing 80% of the Drummond Report's recommendations (Ontario Liberal Party, 2014).

Given the Ontario government's mandated commitment to using “evidence-based policy and appropriate metrics,” (Wynne, 2014) it seems likely that only those programs that show measurable benefits may survive the chopping block.

Benefits evaluation schemes tend to evaluate programs in isolation. That is, they assume there is a simple causal link between a service or package of services and one or several measurable outcomes. However, the present study indicates that evaluating programs in isolation will not always reveal their effect when combined with other programs. If we focus on a specific service and the impact of that particular service on a defined outcome, we may be inclined to conclude that the service is unimportant if the observed outcome is smaller than desired. Similarly, a narrow view of program efficacy might lead to the belief that a specific service can only be expected to effect change on a single designated outcome. The results of the current study indicate that when parents perceive that they are supported in general across areas of both child and family need, they have a more positive view of their children’s well-being. This implies that many support programs may produce greater benefits to a child's overall well-being as part of a package of programs than they would individually. Measuring any one program individually, in the absence of broader supports and services, may therefore fail to reveal its potential.

The results of the present study suggest that the prevailing single-program approach to benefits evaluation is flawed, but there are no easy ways to measure the complex interactions between support programs. Even with the best of intentions the ever present constraints on time, money, and personnel may mean that policy makers will be forced to rely on single-program evaluation schemes. One actionable suggestion from the present study is simply that policy makers keep the limitations of single-program benefits evaluation schemes in mind. These evaluations may miss important aspects of program efficacy, and by being aware of this it may be possible to avoid underestimating programs. Furthermore, if there is a chance to perform a more holistic benefits evaluation, this should be recommended, as each individual and family is unique and will have their own priorities (Mitchell & Sloper, 2003).

Translating research into policy and practice. The implications of the present study were explored at two knowledge translation events held in the fall of 2014. These events brought together stakeholders who self-identified as parents, clinicians, service managers, researchers, and policy makers, and provided them with a chance to make recommendations for translating these research findings into policy and practice. The following discussion will focus on recommendations provided by participants who attended the session at the Canadian Association of Paediatric Health Centres (CAPHC) Annual Convention in Calgary, Alberta on October 20, 2014.

Discussions at the CAPHC symposium were lively, and the topic appeared to resonate with most attendees. Through an interactive activity participants provided recommendations, and then rated each other's recommendations. These ratings provide valuable insight into participant perceptions of each suggestion. The most highly rated responses were:

- "As a parent, I think supports for parents' mental health/well-being need to be made known to parents and made available,"
- "As a parent, I want to have the child followed by services, so that at school, at home, hospital there is continuity of care for the child. Feeling that your child is accepted 'as is' not to be 'fixed',"
- "As a parent, mental health services and system integrated with rehab services in community and school. Holistic approach to my child and family," and
- "Include/invite parents to discuss and identify what they perceive their needs are when contemplating/designing services."

Several central themes emerged from the overall participant responses, and most of them are embodied in the suggestions presented above. The most common theme was that of *continuity of care*, which encompassed notions of, for example, coordination, integration, and longitudinal following. A smaller number of participants expanded upon this need for continuity of care, suggesting a greater role for *service coordinators* to help parents navigate the many systems of care. Similarly, some respondents indicated that part of providing continuity of care involves less rigid thinking about the *locations* in which support is provided, suggesting that services should be available wherever families need them. *Asking parents* what is important to them was the second most highly endorsed theme to emerge. In general, respondents who wrote about the need to ask parents did so in relation to gaining parent and family input on individual needs, priorities, and goals. Some attendees recommended that *tools* be used to help families identify their priorities and track progress toward individual goals. Many participants discussed the theme of *parent mental health*. The recommendations indicated the importance of promoting the mental health of parents as part of support provided to children. Another recurrent theme was that of a need for *information*. This theme included suggestions for providing families with information about available services, as well as suggestions for gathering information from families and service providers about existing service needs. There was a sense from the recommendations that both parents and service providers were often in need of this information, and more could be done to disseminate information to those who would benefit from it. Several attendees brought up the theme of *cross-ministry collaboration*, stating that there is often little communication between the various ministries that serve children (e.g., health, children and youth services, education). A recommendation that was put forward by multiple participants in response to this need for cross-ministry collaboration was to create *central databases* that would link service providers and that would provide families with central sources of information and resources. Finally, there was a sense that there should be a *focus on overall goals* rather than on the number of unique clients seen or on specific performance metrics, with calls for funding to be tied to well-being and social determinants of health.

Regarding the theme of continuity of care, participants indicated that there was a need for services to be integrated, not only across time and space, but also across disciplines. This notion of satisfaction being tied to parent perceptions of service adequacy ties into the second theme of asking parents for their input, and together these two constructs are directly related to the results of the present study. When CAPHC participants discussed continuity of care they highlighted the importance of coordination, integration, and longitudinal following. This may be interpreted as acknowledgement that the lives of children with NDD are complex, and so too are the systems of care that they must navigate. Participants at the CAPHC conference recommended that parents be consulted so that services meet the specific, and often complex, needs of their children and families. Some participants proposed that tools should be used to elicit and record parent priorities. The current study supports the use of AMC-26 for just such a purpose. AMC-26 was found to be a reliable and valid measure of parent reported concerns about child functioning. Given the ease of use and interpretation of AMC-26, this checklist may therefore serve to guide conversations with parents about their needs and priorities for their family. Although further research is required to investigate the appropriateness of AMC-26 as a tool to track change over time, the results of the current study, together with the recommendations of the CAPHC participants, suggest that there is a desire for comprehensive longitudinal following, and AMC-26 may prove to be an effective tool to facilitate dialogue with families over time.

Implications for Practice

The findings have additional implications for the clinical practice of service providers working with children with NDD and their families. First, the results of the current study should inform clinicians of the importance of assessing the psychosocial functioning of parents as part of their assessment of children and that supports and services for the whole family should be implemented as part of children’s intervention plans. The emphasis throughout this paper has been on a holistic model of child well-being that encompasses environmental factors, including the role of parents. In line with the theoretical framework, the Supports and Services Questionnaire used in this study examined the perceived adequacy of services for both the child and the family. As described at length in earlier sections of this paper, parent mental health has been shown to relate to child function and the extent to which parents feel they are supported in their parenting role has been shown to impact parent well-being.

Models of family-centred care developed over the past 30 years (e.g., Trivette, Deal, & Dunst, 1986; Dunst & Trivette, 2009) have now been extensively investigated and there is a large body of empirical work attesting to the importance of providing services to children in a family-centred manner (e.g., Dunst, Boyd, Trivette, & Hamby, 2002; Dunst, Trivette, & Hamby, 2007; Law et al., 2003; Trivette, Dunst, & Hamby, 2010; Trute, Hiebert-Murphy, & Wright, 2008). A recent investigation using meta-analytic structural equation modeling found that across eight studies comprising 910 children and their parents, family-centred service was associated with parent self-efficacy and well-being as well as with parent-child interactions and child development (Trivette et al., 2010). It is therefore not surprising that hospitals have begun to adopt family-centred models, adherence to which appears to have increased in recent years. For instance, leading paediatric hospitals across Canada all have patient and family-centred care mandates, which often include centres of innovation dedicated to supporting families (e.g., Alberta Children's Hospital, 2011; Holland Bloorview Kids Rehabilitation Hospital, 2013; Hospital for Sick Children, 2014; Montreal Children's Hospital, 2015). Although the mandates vary in their breadth and specificity, at the heart of all of them is the recognition that involving family members is important for promoting healthy child development. A central theme to emerge across mission statements is that of families as partners in decision making and care (e.g., Holland Bloorview Kids Rehabilitation Hospital, 2013).

However, what is absent from many, although not all, of the hospital models of family-centred care is the provision of supports to family members and not just children. The results of the current study suggest that this is a shortcoming of existing service models. In fact, the recommendation that emerged from the CAPHC discussion, which suggested that parent mental health must be prioritized as part of services for children, is directly in line with findings from the research literature and with the results of the current study. Findings from a qualitative investigation of a sample of mothers of children with autism help to elucidate the ways in which current clinical practice can be improved. Larson (2010) conducted in-depth interviews with nine mothers of boys with autism and found that the mothers' parenting experiences could be characterized as vigilance. Larson notes that using the word "vigilance," rather than "stress" or "burden," allowed for a less negative lens through which to view the parenting role. Mothers in this study reported being vigilant 24 hours a day, seven days a week. Mothers' vigilance required that they be attuned to their sons' emotional states, ready to intervene should their children not be able to regulate their own emotions or behaviours. Vigilance also involved attention to the surrounding environment, being watchful for potential triggers and then being ready to intervene in order to mitigate the impact of environmental stressors. This level of vigilance was considered to be higher than that of mothers of typically functioning children and was reported to be very draining, with mothers feeling as though they had no respite from being vigilant. The author states that clinical services for children do not typically address maternal mental health, yet the levels of vigilance experienced by these mothers might have accounted for decreased maternal well-being, which would have had indirect implications for the health and well-being of their children and families. Larson therefore suggests that front-line clinicians are ideally situated to take a lead role in supporting parental mental health as part of service provision for children, with this being an important area for improvement in the way services are currently provided.

A second and related implication for practice to emerge from the study findings is the importance of connecting families with the supports and services that they and their children need, when they need them. Proving the level of support that is needed was found to have a positive association with children's well-being. Similarly, a lack of timely support may have deleterious effects. Therefore, clinicians should be made aware of these findings in order to provide sufficient support to families. Minnes and Steiner (2009) arrived at a similar conclusion following a series of semi-structured interviews conducted with parents of youth with ASD (*n* = 3 mothers), fragile X syndrome (*n* = 5 mothers; *n* = 2 fathers; *n* = 1 foster mother), and Down syndrome (*n* = 4 mothers; *n* = 2 fathers) regarding their perceptions about the services they were receiving in the province of Ontario. These researchers found that across diagnostic groups, parents reported many barriers to accessing services. Parents stated that they had to advocate for access to services and this could be challenging if they did not know for what they should be advocating. Minnes and Steiner also found that for the families of children with ASD or fragile X syndrome accessing appropriate diagnostic assessment services proved challenging. Furthermore, several parents indicated that once they received a diagnosis the process of finding appropriate services was still difficult, and they expressed a need for more coordination of services. This sentiment is in line with some of the themes that emerged from the CAPHC participants, indicating that continuity of care may be an important area in which clinicians should focus when providing services for families of children with NDD. Additional support for this hypothesis comes from Miller, Condin, McKellin, Shaw, Klassen, and Sheps (2009) who conducted in-depth semi-structured interviews with parents of children with chronic conditions (n = 47 parents) in the province of British Columbia. Children's diagnoses included spina bifida, Down syndrome, attention-deficit/hyperactivity disorder, Duchenne muscular dystrophy, and cystic fibrosis. These parents reported barriers to their children's continuity of care, including insufficient communication between service providers and a lack of coordination between services. For some, these barriers were overcome by parents' own assumed service coordinator roles, although this was reported to be tiring and inefficient. Good communication and solid relationships with clinicians were seen by parents as integral to achieving continuity of care (Miller et al., 2009). Therefore, clinicians should be mindful of the importance of supporting parents in accessing, coordinating, and managing those services that their children and families need.

Limitations

It is important to acknowledge some of the limitations of this study. One limitation is the use of convenience sampling, both for the larger study and for the subsample. The institutions from which participants were recruited imposed their own parameters for the client populations that could be approached and for the method of inviting families to participate. In addition, the package of parent questionnaires was lengthy and parents reported that it took them between two to four hours to complete it. The time commitment required to complete the questionnaires might therefore have been a factor in attrition from the study. Recruitment of the subsample was based primarily on participants' previously expressed interest in participating in the child testing and on participants' geographical proximity to the primary investigator (A.R.). It was not within the scope of the present study to include more than 50 participants in the subsample, therefore once 50 participants had been recruited, subsample recruitment stopped. Therefore, there might have been more families willing and able to participate in the subsample study that were not offered the opportunity to do so. The inclusion criteria for this study required that participants have at least a Grade 5 level of English language reading comprehension. Unfortunately, it was not within the scope of the current study to provide translation for families who had insufficient English reading proficiency, thus these families would have been excluded from participating. Another limitation is that children's diagnoses were not independently verified. The majority of children were recruited through hospital clinics for which an appropriate NDD diagnosis was a requirement for service. However, in most cases research assistants did not have access to full medical charts and therefore, verification of diagnoses reported by parents was not possible. Finally, mothers were over-represented, with significantly fewer fathers participating than mothers. Given the literature that shows fathers' increasing involvement in childcare (Pruett, 1998) as well as the important role that fathers play in their children's development (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005; Pruett, 1998), efforts were made throughout the recruitment and data collection process to encourage fathers' participation. For instance, whenever both parents were present at the time of recruitment research assistants emphasized the importance of obtaining both mothers' and fathers' perspectives and encouraged both parents to participate. In the majority of cases recruitment occurred in conjunction with a family's attendance at their child's medical appointment. When only one parent attended their child's appointment the attendant parent (usually the mother) was encouraged to share the study information with the child's other parent. Therefore, mothers frequently served as gate keepers to their children's fathers and only limited follow-up was possible with many of these fathers. A further difficulty with this sampling approach is the increased likelihood for sampling bias. There is evidence that recruiting fathers through mothers increases the likelihood that recruited fathers will have higher education and incomes, that they will be married, and that they will have positive spousal relationships (Cabrera, Shannon, West, & Brooks-Gunn, 2006; Mitchell, See, Tarkow, Cabrera, McFadden, & Shannon, 2007; Tamis-LeMonda, Shannon, Cabrera, & Lamb, 2004). It has been suggested that researchers often overlook the importance of examining mothers' and fathers' perspectives separately (Phares et al., 2005) and that too many researchers fail to provide important information regarding sampling procedures, response rates, and reasons for non-participation of fathers (Costigan & Cox, 2001). In the current study sample size differences between mothers and fathers were too great to allow statistical comparison between groups, although efforts were made to clearly describe the sample. Overall, the participants in this study reported high rates of two-parent households, were well-educated, were economically advantaged, and significantly more mothers than fathers participated. Therefore, the generalizability of the results is limited.

Another limitation of this study was the use of parent reports for each of the variables in the SEM model. With the same respondents answering questions about adequacy of supports and services, degree of functional impairments, and overall well-being it is possible that rater bias may have been a factor in the observed relationships. Nevertheless, the results from the AMC-26 validation study suggested a high degree of correlation between parent reports of their children's functional difficulties and more objectively assessed functioning, indicating that parents were accurate reporters of their children's functioning. A related limitation concerns the limited existing evidence regarding the validity of AMC-26 as a measure of child function. AMC-26 is currently undergoing validation through *CanChild*, and thus far no studies have been published regarding the validity of AMC-26.

Some limitations can also be raised concerning the measure used to examine adequacy of supports and services, the Supports and Services Questionnaire (SSQ). First, the SSQ authors report that the SSQ was intended as a list and not a scale. Summers stated that the items were not designed to cluster together as factors; rather the list could be used to determine which services individuals did and did not have (Email correspondence between D. McCauley & J. A. Summers, October 20, 2008). Therefore in the present study the calculation of a total score, representing the number of services that children and families had, was determined to be an acceptable scoring approach and was arrived at through expert consultation (P. Rosenbaum & L. Lach, personal communication, December 2, 2010). Second, the SSQ did not allow for an investigation of the factors that influenced parents' reports of service adequacy. Absent in the data presented is any account of whether children had previously received adequate services in a particular area but were no longer receiving services that caregivers perceived to be necessary. The measure also failed to capture whether parents' satisfaction with services was influenced by a lack of public funding or access to publicly funded services. However, although the SSQ relied on parent reports and did not elucidate the nuances outlined above, the questionnaire nevertheless provides valuable information regarding parent perceptions of the adequacy of their supports at the time, irrespective of why they may or may not be satisfied.

Directions for Future Research

The results of the current study open up several avenues for further research. For instance, the current study presents preliminary information about the reliability and validity of AMC-26. Further work is required to establish the factor structure that was identified. This task is currently being undertaken by two separate research groups, using different samples of children with NDD (*CanChild* research group, personal communication, August 28, 2014; E. Gardner, personal communication, January 15, 2015). Additional research is warranted to examine the factor structure in a control sample of children without NDD. Moreover, the current study did not examine the test-retest reliability of AMC-26. Therefore, further research is needed to determine this aspect of reliability for AMC-26. The significant positive relationship found between child functional difficulties, as assessed by AMC-26, and parent depressive symptoms was expected given the literature that shows correlations between child function and parent well-being. However, the relationship is one that bears further investigation because if the relationship holds, then clinicians using AMC-26 should be informed about the utility of AMC-26 to provide insight into the well-being of caregivers. Clinicians who use AMC-26 and obtain parent reports of high numbers of functional concerns should then follow-up regarding the well-being of parents. Further investigation into the relationship between child functional concerns on AMC-26 and parent depressive symptoms is also warranted to control for the possibility of confounding results due to common respondents. As discussed in an earlier section, the current study used responses from the same participant to inform on both child functional concerns and parent depressive symptoms. Future studies should consider collecting functional concerns from one parent and depressive symptoms from the other, in order to minimize confounds.

In order to facilitate comparison between mothers' and fathers' reports, future studies should also attempt to increase the number of parent dyads recruited. This recommendation is in line with earlier discussion that highlighted the overrepresentation of mothers compared to fathers in the current study. Although efforts at recruiting fathers were made in the present investigation, the observed disparity suggests that extraordinary recruitment and retention strategies may be required in order to involve fathers. As part of a related project, another researcher with the Parenting Matters! study is investigating the role of fathers. Her research may shed light on the factors affecting fathers' participation. Researchers should be mindful of the need for different recruitment approaches for fathers and should be encouraged to push for greater participation of fathers in parenting research. The current study was also limited by the relatively affluent nature of the sample. Future research should attempt to engage parents who have lower SES or who are not proficient in English, particularly given that there may likely be socio-economical barriers limiting the participation of these families and similarly, there may be other important characteristics of these families that are absent in our current interpretation.

The recommendations put forward by the CAPHC conference participants suggest that satisfaction with services might be influenced by the extent to which parents feel that their service needs are being met in a comprehensive fashion. A limitation of the current study is the lack of explanatory power afforded by the SSQ. Future research would benefit from coupling the SSQ with follow-up interviews to investigate the ways in which parents feel their service needs are met or unmet. Interviews might also elucidate questions about who is providing services (e.g., public versus private) and whether a currently unmet need was previously met and vice versa. This type of information will be necessary in order to make the types of changes suggested in the policy and practice implications sections. Therefore, this is certainly an avenue for future empirical investigation.

Conclusion

The results of the current study add to our understanding of the importance of looking at the multiple dimensions involved in children's well-being. From a community service perspective, agencies should consider how to promote the participation and engagement of children with NDD *and their families*. In order to increase participation, greater attention must be paid to providing the particular constellation of supports and services that each child requires in order to promote his or her well-being within the context of the family, the community, and society at large. Families have been telling us that they need more supports and that greater support leads to greater well-being for parents and children. The present study provides empirical evidence that these contentions are valid. It is time that we listened.

Statement of Original Contribution

The current study makes several original contributions to our understanding of well-being for children with NDD. First, this study extended existing empirical evidence of a relationship between child functioning and parent well-being, and suggested a similar relationship might hold for children themselves. The results confirmed this hypothesis, demonstrating that parent perceptions of their children's functional difficulties were predictive of their children's well-being. In so doing, the results provide new information regarding pathways to improving the well-being of children with NDD. For instance, service providers and clinicians working with families of children with NDD should be made aware of the important role that parent perceptions of child function can have on their appraisals of child well-being. Working with parents to reduce the number of concerns they have regarding their children's functioning may have significant positive benefits to parents' perceptions of their children's well-being, which may in turn have a positive cyclical effect on family climate and the well-being of all family members. This study was the first to examine this relationship between parent concerns about their children's functioning and parent appraisals of their children's well-being, and therefore contributes important information to our understanding of well-being in this population.

Second, the current study used a measure of supports and services that included both child and family service needs, and then examined the relationship between this construct of child and family supports and services and child well-being. The finding of a significant indirect relationship between child and family supports and services and child well-being, whereby parent perceptions of children's functional difficulties mediated the relationship, provides new information concerning the importance of adequately supporting all family members in order to promote the well-being of children with NDD.

Third, the present study added a subsample of participants with whom direct cognitive and adaptive assessments were completed, providing strong evidence of the reliability and validity of AMC-26. The results provide empirical support for the use of AMC-26 as both a clinical and research tool for examining parent perceptions of their children’s functional difficulties. Given the strong correlations obtained between AMC-26 and the direct assessment results, clinicians and researchers can feel confident using AMC-26 whenever a shorter tool would be more appropriate than a much longer comprehensive assessment. There are many instances when it would not be feasible to conduct a cognitive and adaptive assessment, whether due to time, scope of practice, or resource constraints. Rather than sacrificing the information that would be obtained from direct assessment, clinicians and researchers can use AMC-26 to obtain a reliable overall understanding of children’s functional difficulties, which might later be followed up with more in-depth assessment. The results of the current study are the first documented reliability and validity testing of AMC-26 and are therefore an important contribution to the development of AMC-26 as a measurement tool.

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Appendix A

About My Child, 26-Item Version (AMC-26)

About My Child, 26-Item Version (“Parental Checklist of Function”)

© Rosenbaum, P., Mesterman, R., Law, M., Jaffer, S., Russell, D., Gorter, J.W., ... Kertoy, M. (2008)

Our Concerns about Our Child’s Function

- Please fill in every row by ticking either “yes” or “no” on each line

Compared to other children of the same age, I am concerned about my child’s:		**If YES, does this impact on their ability to participate in everyday activities?**
Ability to move around at home, school and community	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Ability to use their hands and arms to do the things they want to do	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Daily Activities *such as*		
• Feeding / eating	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Toileting	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Dressing/undressing	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Sleeping	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Seeing	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Hearing	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot

Compared to other children of the same age, I am concerned about my child's:		**If YES, does this impact on their ability to participate in everyday activities?**
Ability to communicate		
• Ability to understand other people	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Ability to tell people what they want	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Clarity of speech/language	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Behaviour: My child is often…		
• Aggressive toward others	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Overactive and too 'busy'	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Too quiet and shy	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Mood: My child is often…		
• Irritable and cranky	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Anxious and worried	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Sad and moody	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot

Compared to other children of the same age, I am concerned about my child's:		**If YES, does this impact on their ability to participate in everyday activities?**
Thinking and learning abilities: My child has…		
• Trouble to learn new things	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Trouble to remember things they know	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Trouble to say what they mean	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Social skills with children. My child is often…		
• Shy	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Slow to make friends	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
• Aggressive	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Social skills with adults. My child is often…		
• Rude	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Participation in activities outside of school		
• My child is a loner	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot

Compared to other children of the same age, I am concerned about my child’s:		If YES, does this impact on their ability to participate in everyday activities?
Participation in activities outside of school		
- My child doesn’t want to do outside activities	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Are there any other functional/behavioural problems which worry you? Please describe these in your own words.		

Appendix B

Quality of Life Measure for Children with Developmental Disabilities: Parental Perspective

Quality of Life Measure for Children with Developmental Disabilities: Parental Perspective

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The questions that follow ask for your view of your child's quality of life. They address issues in 3 areas:

Being: Who your child is perceived to be
Belonging: Your child's connections to people and places
Becoming: Your child's nurtured growth and development

Answer each of the questions using the 3 scales:

How much does this statement *apply* to your child's situation right now?
How *important* is this for your child?
How *satisfied* are you with the way things are?

BEING
Who my child is perceived to be

		How much does it apply?	How important?	How satisfied?
1.	Other people treat my child first and foremost as a child.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
2.	Other people treat my child as a child with a disability.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
3.	Other people see only my child's disability.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
4.	My child is like any other member of my family.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
5.	My relatives treat my child like any other member of the family.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
6.	My child is like any other member of the community.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
7.	Other people treat my child like any other member of the community.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)

How much does this statement ***apply*** to your child's situation right now?				
1 Does not apply	2 A little	3 Somewhat	4 Very much	5 Extremely well

How ***important*** is this for your child?				
1 Not important at all	2 Not very important	3 Important	4 Very important	5 Extremely important

How ***satisfied*** are you with the way things are?				
1 Not at all satisfied	2 Not very satisfied	3 Satisfied	4 Very satisfied	5 Extremely satisfied

BELONGING
My child's connections to people and places

		How much does it apply?	How important?	How satisfied?
8.	People in my family include my child in family activities and occasions (e.g., family gatherings, gift-giving, family traditions, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
9.	My child plays with her/his brother(s) and sister(s).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
10.	My child has good relationships with her/his relatives (e.g., relatives make a fuss over the child).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
11.	My child plays regularly with other children.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
12.	My child has friends.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
13.	My child is regularly invited to play with other kids.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
14.	My child has fun doing activities with other kids (e.g., summer camp, neighbourhood and community activities, playing in the park, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
15.	People in my community include my child (e.g., greet and talk to my child, welcome my child in our place of worship, in activities in the local community centres, at community events and activities, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
16.	People in my child's school are good for my child (e.g., teachers, peers, E.A.'s, administrative staff, custodial staff, etc., are supportive, helpful, and friendly).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)

How much does this statement ***apply*** to your child's situation right now?				
1 Does not apply	2 A little	3 Somewhat	4 Very much	5 Extremely well

How ***important*** is this for your child?				
1 Not important at all	2 Not very important	3 Important	4 Very important	5 Extremely important

How ***satisfied*** are you with the way things are?				
1 Not at all satisfied	2 Not very satisfied	3 Satisfied	4 Very satisfied	5 Extremely satisfied

BELONGING
My child's connections to people and places (continued)

		How much does it apply?	How important?	How satisfied?
17.	People who understand how my child's disability affects my child treat my child better than people who do not know about her/his disability.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
18.	My family members are able to understand what my child says/communicates.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
19.	Professionals are able to understand what my child says/communicates.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
20.	My child's friends are able to understand what my child says/communicates.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
21.	Other people in the community are able to understand what my child says/communicates.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
22.	My child's behaviour is affected when other people don't understand her/his communication (e.g., acts up, becomes quiet etc.)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
23.	Our house suits my child's needs (e.g., home adaptations, special equipment, useable space, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
24.	My child is able to go to her/his neighbourhood school or day care.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
25.	My child's school or day care is set up in ways that meet my child's needs (e.g., the child can use the bathroom, access lockers, a time-out is available if required, elevators are available if needed, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)

How much does this statement ***apply*** to your child's situation right now?

1	2	3	4	5
Does not apply	A little	Somewhat	Very much	Extremely well

How ***important*** is this for your child?

1	2	3	4	5
Not important at all	Not very important	Important	Very important	Extremely important

How ***satisfied*** are you with the way things are?

1	2	3	4	5
Not at all satisfied	Not very satisfied	Satisfied	Very satisfied	Extremely satisfied

BELONGING
My child's connections to people and places (continued)

		How much does it apply?	How important?	How satisfied?
26.	Professional services suitable for my child are easily accessible.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
27.	Parks, playgrounds, and pools in the community are accessible for my child.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
28.	The usual places for entertainment (e.g., theatres, malls, restaurants) are accessible for my child.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
29.	We have access to transportation that lets my child participate in school and community activities.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
30.	My child feels safe with certain people she/he sees often (e.g., neighbour, teacher, doctor, peers, babysitter, respite care, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
31.	My child feels secure with certain people she sees often.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
32.	My child feels safe playing with other kids.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)

How much does this statement ***apply*** to your child's situation right now?				
1 Does not apply	2 A little	3 Somewhat	4 Very much	5 Extremely well

How ***important*** is this for your child?				
1 Not important at all	2 Not very important	3 Important	4 Very important	5 Extremely important

How ***satisfied*** are you with the way things are?				
1 Not at all satisfied	2 Not very satisfied	3 Satisfied	4 Very satisfied	5 Extremely satisfied

BECOMING
My child's nurtured growth and development

		How much does it apply?	How important?	How satisfied?
33.	Important people in my child's life recognize her/his SPECIFIC needs related to the disability (e.g., people from the government, communities, professionals, school, family etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
34.	People in my child's life recognize her/his needs related to being a child (e.g., love and affection, attention, play, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
35.	Important people in my child's life do the things that make my child happy.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
36.	The government is supporting my family in ways that help to meet my child's needs.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
37.	Professionals providing services are meeting my child's disability related needs.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
38.	Professionals are supporting my family to meet my child’s needs (OT/PT/speech therapists, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
39.	People’s expectations match my child’s abilities.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
40.	My child is supported to do the important things in her/his life to help her/his growth and development (e.g. play, chores, daily living activities).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
41.	My child gets the programs/resources that she/he needs to grow and develop.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
42.	Professional therapists are available for my child when she/he needs them (e.g. speech, OT, PT, behaviour, psychological, medical, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)

How much does this statement ***apply*** to your child's situation right now?				
1 Does not apply	2 A little	3 Somewhat	4 Very much	5 Extremely well

How ***important*** is this for your child?				
1 Not important at all	2 Not very important	3 Important	4 Very important	5 Extremely important

How ***satisfied*** are you with the way things are?				
1 Not at all satisfied	2 Not very satisfied	3 Satisfied	4 Very satisfied	5 Extremely satisfied

BECOMING
My child's nurtured growth and development (continued)

		How much does it apply?	How important?	How satisfied?
43.	In our community there are opportunities for my child to have recreational experiences with other children that foster her/his growth and development.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
44.	My child has opportunities to do the things/activities in her/his community that are meaningful to her/him (e.g. church, Brownies/Cubs, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
45.	The teaching staff at my child's school/day care are providing experiences that help/enable my child to learn important academic skills (e.g., reading, number work, counting, printing and writing, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
46.	The teaching staff at my child's school/day care are providing experiences that help/enable my child to learn important life skills (e.g., toileting, dressing, feeding, social skills, etc.).	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
47.	My family is able to provide opportunities that foster my child's steady growth and development.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
48.	My family receives enough support to enable us to support my child's growth and development.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
49.	What I do for my child's growth and development now is guided by my concern for her/his future.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)
50.	The resources and supports my child has are because of my own efforts.	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)	(1) (2) (3) (4) (5)

How much does this statement ***apply*** to your child's situation right now?				
1 Does not apply	2 A little	3 Somewhat	4 Very much	5 Extremely well

How ***important*** is this for your child?				
1 Not important at all	2 Not very important	3 Important	4 Very important	5 Extremely important

How ***satisfied*** are you with the way things are?				
1 Not at all satisfied	2 Not very satisfied	3 Satisfied	4 Very satisfied	5 Extremely satisfied

OTHER AREAS?

51. Is there any other area(s) that we have not asked you about, that is important to your child's quality of life?

Appendix C

Supports and Services Questionnaire

Supports and Services Questionnaire

This survey has questions about the services you and your child need and/or receive.
When answering these questions, please think about your experiences **over the last 6 months.**

A. Please tell us about the type of services your CHILD **needs and receives.**

Which of the following services…

	Does your **child** currently **need**?	If **YES**, how much service does he or she get?		
Services for your CHILD with special needs:				
		None	Some, but not enough	Enough
1. Behaviour support	☐ Yes →	☐	☐	☐
2.	☐ No (go to next question)			
3. Counseling and psychological services	☐ Yes →	☐	☐	☐
4.	☐ No (go to next question)			
5. Employment or vocational services	☐ Yes →	☐	☐	☐
6.	☐ No (go to next question)			
7. Health services (medical evaluations, nutrition, nursing)	☐ Yes →	☐	☐	☐
8.	☐ No (go to next question)			
9. Hearing services	☐ Yes →	☐	☐	☐
10.	☐ No (go to next question)			
11. Occupational therapy	☐ Yes →	☐	☐	☐
12.	☐ No (go to next question)			
13. Physical therapy	☐ Yes →	☐	☐	☐
14.	☐ No (go to next question)			
15. Recreational therapy	☐ Yes →	☐	☐	☐
16.	☐ No (go to next question)			
17. Service coordination	☐ Yes →	☐	☐	☐

Which of the following services… Services for your CHILD with special needs:	Does your **child** currently **need**?	If **YES**, how much service does he or she get?		
		None	Some, but not enough	Enough
18.	☐ No (go to next question)			
19. Special equipment to help your child live, learn, and grow (assistive and communications technology)	☐ Yes →	☐	☐	☐
20.	☐ No (go to next question)			
21. Speech and/or language services	☐ Yes →	☐	☐	☐
22.	☐ No (go to next question)			
23. Transition services	☐ Yes →	☐	☐	☐
24.	☐ No (go to next question)			
25. Transportation and/or mobility services	☐ Yes →	☐	☐	☐
26.	☐ No (go to next question)			
27. Vision services	☐ Yes →	☐	☐	☐
28.	☐ No (go to next question)			
29. Other, please describe: ______________________________	☐ Yes →	☐	☐	☐
30.	☐ No (go to next question)			

B. Please tell us about the type of services/supports your FAMILY **needs** and **receives**.

Which of the following service… Services/supports for your FAMILY:	Does your **family** currently **need**?	If YES, how much service/support does your family **receive**?		
		None	Some, but not enough	Enough
1. Child care	☐ Yes →	☐	☐	☐
2.	☐ No (go to next question)			
3. Counseling	☐ Yes →	☐	☐	☐
4.	☐ No (go to next question)			
5. Homemaker and/or housekeeping services	☐ Yes →	☐	☐	☐
6.	☐ No (go to next question)			
7. Information about legal rights	☐ Yes →	☐	☐	☐
8.	☐ No (go to next question)			
9. Information about specific disabilities	☐ Yes →	☐	☐	☐
10	☐ No (go to next question)			
11 Information about where to get services for your child	☐ Yes →	☐	☐	☐
12	☐ No (go to next question)			
13 Information about where to get services for your family	☐ Yes →	☐	☐	☐
14	☐ No (go to next question)			
15 Money to help pay bills	☐ Yes →	☐	☐	☐
16	☐ No (go to next question)			
17 Parent or family transitioning	☐ Yes →	☐	☐	☐
18	☐ No (go to next question)			
19 Sibling support	☐ Yes →	☐	☐	☐
20	☐ No (go to next question)			

Which of the following service… Services/supports for your FAMILY:	Does your **family** currently **need**?	If YES, how much service/support does your family **receive**?		
		None	Some, but not enough	Enough
21 Support groups	☐ Yes →	☐	☐	☐
22	☐ No (go to next question)			
23 Respite care	☐ Yes →	☐	☐	☐
24	☐ No (go to next question)			
25 Transportation	☐ Yes →	☐	☐	☐
26	☐ No (go to next question)			
27 Other, please describe: ______________________________	☐ Yes →	☐	☐	☐
28	☐ No (go to next question)			