

April 2016

# An Examination of Risk Factors Among Male Children and Youth with Complex Special Needs

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Graduate Program in Education

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Arts

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## Recommended Citation

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### **Abstract**

Children and youth presenting with complex special needs (CSN) experience a variety of different developmental and health problems and require multiple services from a range of sectors throughout their lifespan. Despite the extreme vulnerability of this group, little is known about this population. The current study aims to enhance our understanding of the characteristics present among children with CSN by examining risk factors present amongst children and families referred for complex special needs funding. The project utilizes interRAI instruments to examine the combination of risk factors that contribute to the high level of needs of this population. The results from this study suggest that impairments in family functioning and challenges completing activities of daily living predict children most likely to be referred for CSN funding. This project offers several implications for clinicians regarding the unique characteristics that distinguish children and families at the greatest risk and provides recommendations for treatment planning and funding allocation.

Keywords: interRAI, complex special needs, multiple needs, funding referral, risk factors, risk assessment, disabilities, medical complexity, comorbidity

### **Acknowledgements**

I would like to take the time to thank all of the people who made this thesis possible. First, I would like to thank my supervisors, Dr. Shannon Stewart and Dr. Chloe Hamza for their constant support, patience, guidance, and encouragement. Without you two, this would not have been possible.

Thank you to Dr. Alan Leschied, Dr. Jason Brown, and Dr. Susan Rodger. Your wisdom, humor, and support have contributed to the amazing graduate school experience I've had and I am so grateful to have the opportunity to have gotten to know and learn from each of you. A special thank you to Dr. Alan Leschied for his ongoing encouragement and support in the completion of my thesis.

Thank you to my family, partner and friends for their constant support, confidence, and faith in me over the years. To my family - you have been my confidants and have supported me through every hurdle and I wouldn't be where I am if it wasn't for you three. To my partner and best friend, thank you for your constant love, patience, and kindness. To my friends, thank you for your advice, encouragement, and continuous support.

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## Introduction

Mental health disorders are a common occurrence among children and youth in Canada. Recent statistics suggest that approximately 1 in 5 children and youth in Canada are affected by mental health disorders such as depression, anxiety, conduct problems, or attention deficit-hyperactivity disorder (Canadian Mental Health Association, 2014). Many of these children and youth (hereafter referred to as children) require specific time-limited interventions to improve or resolve their symptoms (Clark, O'Malley, Woodham, Barrett, & Byford, 2005). However, a small percentage of these children (approximately 10% of those referred for mental health services) present with increased complexity (Epstein, Kutash, & Duchnowski, 2004; Reid et al., 2011). The expense for caring for these children accounts for a disproportionate portion of health care costs, as these children require “episodic, chronic, and ongoing care” from multiple service sectors (Stewart & Hirdes, 2015).

Of particular interest is the subset of children who present with complex special needs (CSN) and are referred for additional provincial funding to have their intensive service needs met (Teare, 2008). These are typically children who are chronic users of the children's service system who require services throughout their lifespan, but their families do not have sufficient funds to support the children's resource intensive needs (Day et al., 2002; Robinson, Jackson, & Townsley, 2001; Tahhan, St. Pierre, Stewart, Leschied, & Cook, 2010). As a result, these families may be eligible to apply for funding to help subsidize the costly nature of obtaining the required services, as well as compensate for a lack of available services in the community (Petrenchik, 2008). Provincial governments have been known to reserve funding specifically for families of children who may qualify, however, they have been unable to provide funding to every family that applies and policy makers have struggled to identify which families are most in

need of complex special needs funding (Burnside, 2012; Robinson et al., 2001; Spratt, 2010). These difficulties in making decisions around service allocation for children with CSN underscores the need for a system that is better able to distinguish families most in need for additional funds.

In the past, a variety of different terms have been used to describe this population including: multiple disadvantaged, multiple needs, technology dependent, dual diagnosis, medically complex, and complex health needs (Cohen et al., 2011; Davidson, Bunting & Web, 2012; Day, David & Bidmead, 2002; Rosengard, Laing, Ridley, & Hunter, 2007; McArthur & Faragher, 2014). Many of these terms have been used interchangeably, however, with little consensus among care providers across service sectors regarding the defining characteristics of children with high service needs (Day et al., 2002; Teare, 2008). Without a consistent definition, it has been difficult to conduct research with children presenting with complex needs, allocate funding for this population, as well as determine the prevalence of those with complex special needs in the overall population (Burnside, 2012).

More recently, efforts have been made to try and categorize the vast range of children who present with complex special needs (CSN). According to the Ministry of Children and Youth Services (n.d.) in Ontario, children presenting with CSN who may be eligible for CSN funding are children that: a) are under age of 18 and are in need of long term and/or continuous specialized supports, b) have “two or more different special needs” and require integration of services across different sectors (e.g., mental health, disability services, education), and c) have needs based on a variety of comorbid conditions which can include: intellectual and developmental disabilities, physical disabilities, and chronic, terminal and severe physical health illnesses (Ministry of Children and Youth Services, n.d.). These children typically have needs so



complex that they require services that are specialized, intensive, costly, and require a high degree of collaboration (Abbott, Townsley, & Watson, 2005; Calvert & Lightfoot, 2002; Clark et al., 2005; Day et al., 2002; Mental Health Commission, 2012). Despite advances in technology in medicine which have allowed for increased rates of survival amongst children who have complex medical needs (e.g., children born prematurely; Cohen et al., 2011; Hewitt-Taylor, 2005; Nicholl, Doyle, Moran, & Guilfoyle, 2013; Teare, 2008), this population has continued to be identified as being the most fragile, most challenging, and of greatest concern to the health care sector (Bass, Shields, & Behrman, 2004; Calvert & Lightfoot, 2002; Clark et al., 2005; Cohen et al., 2011; Teare, 2008). Although the resource demands of children with CSN are high, little is known about the characteristics that make this population at increased risk for requiring costly services.

One way to identify those families with the greatest need for CSN funding is through an examination of the risk factors that are present among children who have been referred for CSN funding. A risk factor is defined as any characteristic or attribute, internal or external, which can increase the likelihood of an individual developing a disease, condition, or disorder (World Health Organization, 2014), including individual level risk factors, interpersonal risk factors, and environmental risk factors. Identifying risk factors that can contribute to a high needs presentation (and need for additional financial assistance to meet service needs) can serve to inform provincial-level decisions around service allocation. To date, the literature has not yet provided conclusive evidence of which risk factors are consistently present among families seeking additional financial support. This shortcoming could be due to limitations in existing research with respect to inconsistencies around defining and assessing complex special needs among children and the use of assessments tools that are not comprehensive and have

questionable psychometric properties. Therefore, further research is needed to distinguish risk factors present among those children and their families seeking additional funding as a result of the child's highly complex service needs.

To address the aforementioned limitations of research in this area, this project examined several risk factors that may be associated with families requiring additional funding by utilizing data from comprehensive assessment tools encompassing various areas of risk. By investigating the risk factors present among those families seeking CSN funding, researchers and clinicians will be able to: a) obtain a better understanding of the characteristics that distinguish children and families applying for funding b) obtain a better understanding of the needs of children and families referred for funding, c) enhance their ability to identify children at highest risk for funding referral, thereby increasing the chances of early intervention and, d) develop decision-making tools that will be essential for creating policy guidelines and determining funding allocation.

### **Literature Review**

There are multiple risk factors that may be associated with an increased risk for CSN funding referral among children (Day et al., 2002; Kim-Cohen, 2007). Presumably, the nature and degree of risk factors that are present will influence the extent of additional funding that will be required for a child with CSN (Burnside, 2012; Davidson et al., 2012; Day et al., 2002; Spratt, 2011). In many cases, being exposed to two or more risk factors exponentially increases the likelihood for poor adjustment and adverse outcomes (Burnside, 2012; Davidson et al., 2012; Kim-Cohen, 2007; Rutter et al., 1975). Further, when considering children with complex needs, it is not only the accumulation of factors, but also the interaction between different factors that

contributes to the high needs amongst this population (Burnside, 2012; Kim-Cohen, 2005; Ministries of Health and Education & Department of Child, Youth, and Family Services, 2005).

Recent efforts have been made to identify the risk factors present among children with complex needs. Due to inconsistencies with the terminology surrounding CSN and the broad range of children who fall under the umbrella of complex needs (e.g., children with intellectual disabilities, comorbid conditions, medically fragile children), literature involving children who present with a great depth (i.e., profound, intense or serious level of need) and breadth of need (i.e., having more than one need; Davidson et al., 2012; Rosengard et al., 2007; Rankin & Regan, 2004) was utilized in order to obtain a preliminary understanding of the risk factors that may be relevant for the diverse group of children referred for CSN funding.

### **Disabilities**

Children with CSN have been known to present with physical, neurological, intellectual, and/or developmental disabilities (Burnside 2012; Carnaby, 2007; Coller et al., 2015; Kennedy et al., 2007; Vig, Chinitz, & Shulman, 2005). These disabilities can range in frequency and severity (i.e., mild, moderate, severe, or profound) and can have a varying impact on children and their families (American Psychiatric Association, 2013). Disabilities have been known to contribute to: lower intelligence, poor problem solving skills, impaired cognitive ability, decreased school performance, and emotional and behavioral difficulties among children (Murray, 2003; Vig et al., 2005). Some examples of disabilities that children may present with include: autism, Down syndrome, cerebral palsy, spina bifida, and global developmental delay (Burnside, 2012; Coller et al., 2015; Tean, 2014).

Children who present with more severe disabilities have been known to face difficulties with daily activities requiring assistance and supervision throughout the day (Rosengard et al.,

2007; Pastor, Reuben, & Loeb, 2009; Roberts & Lawton, 2001). For some of these children, their deficits and disabilities interfere with their ability to engage in daily living tasks (e.g., bathing, moving around, etc.) making these children extremely high need (Goddard, Davidson, Daly, & MacKey, 2008; Rosengard et al., 2007). For example, children with intellectual disabilities present with “deficits in adaptive functioning” such that they are unable to be independent and require support from individuals and equipment with “one or more activities of daily living” (e.g., toileting, mobilizing, feeding, washing, etc.; American Psychiatric Association, 2013, p.33).

Approximately one third of the children with severe disabilities require more than three pieces of technology or equipment to engage in daily activities and a large portion require additional supervision with self-care (Department of Health, 2004). Findings from recent studies examining children with complex needs suggest that assistance with the completion of daily living activities is a service often needed for families of children with CSN (e.g., Roberts & Lawton, 2001; Tean, 2014; Thurgate, 2005), however these findings were limited due to inconsistencies in operationalizing CSN, as well as a lack of consistency in the instruments utilized to measure adaptive functioning. When examining children with more severe disabilities, there is an increased dependence upon caretakers and equipment and decreased ability for independence (Department of Health, 2004). A recent report examining children with disabilities in Canada found that 18% of families with children with mild to moderate disabilities required assistance, whereas 55% of children with families with severe or very severe disabilities required assistance (Human Resources and Skill Development Canada, 2006). Children with more severe disabilities are more likely to require ongoing respite care, one to one support, and supervision throughout the day.

### **Comorbidity**

Children with CSN often present with multiple simultaneous health needs, including physical, medical, and mental health concerns (Burnside, 2012; Day et al., 2002; Hewitt-Taylor, 2005; Murray, 2003). Recent statistics suggest that up to 90% of children in foster care with complex needs present with physical health concerns and simultaneous mental health issues (e.g., depression, anxiety, and attachment disorders; Harman, Childs, & Kelleher, 2000). Similarly, children with intellectual disabilities, who often present with complex needs, are twice as likely to present with psychopathology compared to typically developing children (Matson & Matson, 2015; Tonge & Einfeld, 2003; Werner & Stawski, 2012). Moreover, children with medical complexity often present with complex chronic conditions and acute conditions such as cerebral palsy, Down syndrome, and spina bifida (Hewitt-Taylor, 2005; Nicholl et al., 2013; Tean, 2014; Teare, 2008). Complex care children tend to present with functional limitations and are dependent on technology or equipment to optimize their health and/or survive (e.g., feeding tubes, wheelchairs, mechanical ventilation, gastrostomy; Glendinning, Kirk, Guiffrida, & Lawton, 2001; Heaton, Noyes, Sloper, & Shah, 2003; Hewitt-Taylor 2008; Teare 2008). Furthermore, these children present with a high rate of health care utilization (multiple surgeries, long term hospitalization), and require ongoing services from different service providers. The comorbidity of physical/medical and mental health issues of children presenting with CSN increases the complexity of their conditions and places them at a greater risk for high service needs.

### **Family Functioning**

Familial factors play a vital role in contributing to the psychosocial development of children. For example, family dysfunction (i.e., a broad term that has been used generally to refer

to discord within the family unit's level of functioning) has known to be predictive of poor outcomes for children, such as psychiatric illnesses and developmental delays (Hewitt-Taylor, 2005; Landy & Tam, 1998; McArthur & Faragher, 2014). For example, findings from a recent study completed in the United Kingdom on families at risk (reviewed in McArthur & Faragher, 2014), suggested that children who were living in homes with parents who faced multiple disadvantages were more likely to have deprived social networks, negative educational outcomes, poor school performance, and were more likely to be involved with the legal system.

Although family functioning may impact a child's physical and mental health, much of the literature examining families of children with high needs has alluded to the impact the child's condition has on the entire family (McArthur & Faragher, 2014). Family functioning is especially important to consider when discussing children with CSN as these families experience a reduction in their quality of life due to increased responsibility, financial burdens, unpredictable child needs and high levels of stress (Hewitt-Taylor, 2005; McArthur & Faragher, 2014; Nicholl et al., 2013; Reid et al., 2011; Robinson et al., 2001). For some families, their elevations in experienced stress can lead to long term impairments in functioning (Head & Abbeduto, 2007). Overall, when considering children with complex needs, family members have been known to both be affected by their child's condition but also affect their child (Head & Abbeduto, 2007). Common reasons that have been known to contribute to decreased family functioning among these families include: presence of parental illness/disability, poor parent-child interactions, and lack of supports (Hewitt-Taylor, 2009; Teare, 2008).

**Parental Health.** Parental illness (both physical and mental), disabilities, and substance use have been shown to contribute to negative outcomes for children (Burnside 2012; Day et al., 2002; Faller, 2000; Horgan, 2011; Murray, 2003; Preyde et al., 2015). For example, children in

the care of a child welfare agency are at increased risk for having exposure to parental substance use, parental violence, and parental illness and/or disability (Davidson et al., 2012; Day et al., 2002; Devaney, 2004; Sabates & Dex, 2012; Sabates & Dex, 2015). Further, the risk of parenting difficulties, poor attachment, and degree of perceived burden increases when parents present with mental health concerns. Recent studies examining family quality of life have found that children living in families with multiple disadvantages such as parental mental health, substance abuse, or illness were more likely to experience psychosomatic difficulties, sleep disturbances, and have an increased risk of experiencing disorders such as depression and anxiety (Cleaver, Unell, & Aldgate, 2011; Faller, 2000; McArthur & Faragher, 2014; Tunnard, 2004). Moreover, parents presenting with disabilities have reported higher rates of separation and divorce which can further impact the functioning of the family and degree of required support (Human Resource and Skill Development Canada, 2006). The impact of parental factors on child and family outcomes is especially true for maternal illness (e.g., depression; Oyserman, Mowbray, Mearns, & Firminger, 2000; To, Guttman, Dick, Rosenfield, Parkin, Cao, et al., 2004; To, Guttman, Dick, Rosenfield, Parkin, Tassoudji, et al., 2004). Recent studies have found that the presence of maternal depression is common amongst mothers of children presenting with high levels of need (e.g., simultaneous mental health problems; Burnside 2012; Davidson et al., 2012; Fatori, Bordin, Curto, & De Paula, 2013; To, Guttman, Dick, Rosenfield, Parkin, Tassoudji, et al., 2004). Maternal depression has also been known to increase children's risk for psychopathology (e.g., behavioral, externalizing, and internalizing problems), depression among young adolescents, and likelihood of out of home placements (Burke, 2003; Cummings & Davies, 1994; Goodman et al., 2011; Oyserman et al., 2000).

The relationship between parental wellbeing and child wellbeing is unclear, as circular causality can explain poor outcomes for both the parent and the child (Davidson et al., 2012). For example, having a child with intense emotional and behavioral difficulties can affect parental mental health, which can further aggravate symptoms the child presents with and this cyclical pattern can continue. Therefore, it is important to note that although there may be a relationship between parental functioning and a child's functioning, the relationship is complex and may be bidirectional in nature (Davidson et al., 2012; McArthur & Faragher, 2014).

**Parent-Child Interactions.** Poor parent-child interactions and insecure attachment, which can develop as a result of a variety of factors, can contribute to emotional and behavioral problems and impact outcomes for children (Burnside, 2012; Murray, 2003; Perry, 2001; Stewart-Brown & Schrader-McMillan, 2011; To, Guttman, Dick, Rosenfield, Parkin, Cao, et al., 2004; To, Guttman, Dick, Rosenfield, Parkin, Tassoudji, et al., 2004; Vig et al., 2005). Parents of children with complex needs have reported feeling overwhelmed by their child's condition and needs, experiencing interruptions in family life due to the involvement of professionals, and have reported chaotic home environments (Burnside, 2012; Day et al., 2002; Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008; Robinson et al., 2001). A recent study conducted by Statistics Canada (2006) found that 46% of parents of children with mild to moderate disabilities reported feeling stressed and overwhelmed; this rate nearly doubled (82%) when examining stress among parents of children with severe to very severe disabilities. These concerns are likely to work in tandem to impact parent's interactions with their children, their health, and overall family functioning.

Another parenting factor that has been associated with the child's physical and mental health is the level of attachment between parent and child (Stewart-Brown & Schrader-



McMillan, 2011). Attachment theory suggests that children's early interactions with their caregivers (i.e., the early emotional relationship established between the child/caregiver) can impact children's perceptions of themselves and of others (Bowlby, 1951; Bowlby, 1988; Burnside, 2011). Moreover, these interactions impact the type of attachment style a child develops: secure or insecure (i.e., avoidant, ambivalent, and disorganized; Perry, 2001). Previous studies of insecure infants suggest that these children are more likely to: have been maltreated by their caregivers, display internalizing, and externalizing behaviors and develop anxiety, depression and attachment disorders later in life (Devaney & Spratt, 2009; Stewart & Rubin, 1995; Vig et al., 2005). Attachment disorders (such as disinhibited social engagement disorder and reactive attachment disorder; American Psychiatric Association, 2013) are generally rare in the broader population (0.9-4.1%), but are more frequent among children in foster care who present with complex needs (38%-40%; Losinski, Katsiyannis, White, & Wiseman, 2016; Minnis et al., 2013). Children with these disorders have been known to present with emotional and behavioral difficulties and additional psychiatric comorbidity (Losinski et al., 2016; Minnis et al., 2013).

**Supports.** Literature has provided strong evidence of the role supports (i.e., social, financial, and professional support) can play in mediating a variety of risk factors including mental illness, abuse, and stress (Baxter, Cummins, & Yiolitis, 2000; Keen, 2007; McArthur & Farther, 2014). For families with children with CSN, obtaining support is especially important as they experience high levels of responsibility, emotional exhaustion, and heightened distress (Kilic, Gencdogan, Bag, & Arican, 2013; Reid et al., 2011; Robinson et al., 2001; Statistics Canada, 2006; Tahhan et al., 2010); however, research suggests that families of children with CSN are often lacking in support (e.g., Brown, Geider, Primrose, & Jokinen, 2011; Carnevale,

Alexander, Davis, Rennick, & Troini, 2006; McArthur & Farther, 2014; Robinson et al., 2001; Webb, Bunting, & Shannon, 2014). A lack of support can further exacerbate the stress experienced by these families and can contribute to feelings of being overwhelmed, discouraged, and alone thereby impacting their family functioning, quality of life, and feelings of competency in meeting the needs of their children. For example, children with complex medical, neurological, and mental health needs are overrepresented in foster care, residential care, treatment-based facilities and other institutions (e.g., youth justice facilities) as families often report feeling ill equipped to care for children with such demanding needs, resulting in out-of-home placements (Burnside, 2012; Tahhan et al., 2010).

In the past, most children with complex health needs received services in the hospital and were provided supports by health care professionals (Hewitt-Taylor, 2005; Teare, 2008). However, recent studies have found that there are a range of benefits (i.e., psychological, developmental, and physical outcomes) in caring for children in their home whenever possible (Hewitt-Taylor, 2005; Robinson et al., 2001). With recent medical and technological advances, it has become possible to care for more children in their homes; however, this increases the degree of responsibility put on the parents and parents have reported experiencing increases in responsibility across a variety of domains (e.g., emotional, physical, and financial; Human Resources and Skill Development Canada, 2006; Statistics Canada, 2006), which further exacerbates family burden and the need to obtain additional support.

The areas in which families report a lack of support include: social support, support from appropriate community resources, professional services, and financial support (e.g., Carnaby, 2007; Department of Health, 2004; Hewitt-Taylor, 2009; Rosengard et al., 2007; Teare, 2008; McArthur & Farther, 2014). Families have reported issues with obtaining and maintaining social

support due to the inability to: spend time with their friends and family, find suitable care takers for relief or short breaks, and engage in community activities due to lack of accessibility for their children. Moreover, for parents with children with serious emotional and behavioral disorders, they report being unable to be involved in outings/activities due to the child's behaviors (Preyde, Cameron, Frensch, & Adams, 2011). In addition to having feelings of alienation from others due to the child's condition, families also indicate the need to be available for the child "day and night" leading to further exhaustion (Contact a Family, 2011; Kilic et al., 2013; Tahhan et al., 2010; Teare, 2008). Moreover, studies examining the challenges frequently faced by families of children with CSN suggest that professionals often lack the skills and necessary training to be able to successfully support the child and family (e.g., Carnaby, 2007).

In addition to the lack of social and professional support, families also experience heavy financial burdens (Kilic et al., 2013; McArthur & Faragher, 2014; Teare, 2008). Recent statistics suggest that the cost of caring for a child who has a disability costs approximately 3 times as much as caring for a child without a disability (Department of Health, 2004). With more children with complex needs being treated at home, families have reported experiencing increased financial burden and economic distress (Hewitt-Taylor, 2005). Many families have reported difficulty maintaining employment or having to accommodate their work lives (e.g., reject jobs, quit working, adjust work hours, turn down promotions, work fewer hours) to be available for their children (Hewitt-Taylor, 2008; Statistics Canada, 2006; Teare, 2008). In a recent study, researchers reported that approximately 16% of mothers of children with physical or mental disabilities were employed, relative to 61% of mothers of children without disabilities (Brazier, 2006). The impact on employment is further exacerbated when considering children presenting with more severe disabilities. For example, a recent study in Canada found that 29% of parents

of children with mild to moderate disabilities had to reduce the number of hours they worked, compared to 50% of parents of children with severe to very severe disabilities (Statistics Canada, 2006). Moreover, families have reported negative consequences of the child's condition on marital or intimate relationships which can further impact the degree of financial, emotional, and physical support available to the family (Kilic et al., 2013; Teare, 2008). Relative to parents with children without disabilities, parents of children with disabilities typically experience greater levels of marital conflict and divorce (Kilic et al., 2013; Tahhan et al., 2010). In fact, statistics suggest that 42% of parents of children with disabilities reported that their child's condition had an impact on their intimate relationships whereas, this rate increased to 57% when examining intimate relationships involving a child with a more severe disability (Statistics Canada, 2006).

### **The Present Study**

In recent years, there have been increased efforts to obtain an understanding of children presenting with CSN. However, current limitations of the literature need to be addressed. These limitations include: a lack of a comprehensive assessment tool(s) that examine various areas of risk, a lack of research examining the role of multiple risk factors associated with CSN, use of measures with questionable psychometric properties, and the limited number of studies examining children who are the most vulnerable and in need of the most support.

First, it is evident that there are a variety of risk factors that can contribute to CSN presentation and result in the need for additional services, supports and financial resources among families. However, the risk factors identified vary from study to study, suggesting there is little consensus regarding the specific predictive factors associated with CSN. It is hypothesized that this disparity in findings occurs because researchers and clinicians utilize a variety of different assessment tools and approaches when assessing children who present with CSN. Interestingly, researchers who tried to

group risk factors to determine if any particular combination of variables could predict high need children found that risk factors did not group together in predictable ways. For example, in an international review of families experiencing multiple adversities, Davidson et al., (2012) attempted to group together combinations of three, four, five, six, and seven plus risk factors to predict complex need families; however, no combination of risk factors accounted for more than 9% of the families.

Many current studies examining risk have been limited by individual surveys that can only “act as proxy measures of risk” (Davidson et al., 2012) and only focus on particular areas of risk (e.g., Adverse Childhood Experience (ACE) questionnaire to evaluate maltreatment; Spratt, 2010). Although studies like these elucidate the impact of maltreatment and how it contributes to poor outcomes among children, research has pointed out the need for a comprehensive standardized assessment tool that can objectively identify different areas of risk and “multiplicity of problems” (Carnaby, 2007; Clark et al., 2005; Spratt, 2010). Comprehensive, well-developed assessments provide high quality data to assist clinicians and policy makers in making informed decisions regarding care planning and funding because they promote a more holistic understanding of the child’s current level of functioning as well as areas of need.

Second, it is important to consider the psychometric properties of instruments used to obtain information regarding risk. For example, a recently study examining poor developmental attainment in children ages 1-5 reported that the measures utilized (i.e., Strengths and Difficulties Questionnaire and Adolescent Health and Development Questionnaire) had questionable validity (To, Guttman, Dick, Rosenfield, Parkin, Cao, et al., 2004; To, Guttman, Dick, Rosenfield, Parkin, Tassoudji, et al., 2004). When utilizing assessments, particularly ones assessing health outcomes and factors, it is crucial to use assessments with good reliability and validity to ensure effectiveness and reduce error (Kimberlin & Winterstein, 2008; Salmond, 2008).

Third, and arguably the most important limitation of the current literature with respect to CSN is the scarcity of literature that has examined the population of children and families who are referred for extensive amounts of government funding to meet their high service needs. Past studies examining children who may have complex needs have been limited to very particular sub-groups (e.g., children in foster homes, residential treatment facilities, etc.) who have known to experience a great degree of physical and mental health difficulties (Aguilar-Vafaie, Roshani, Hassanabadi, Masoudian, & Afruz, 2011; Bass et al., 2004; CONTACT Hamilton, 2005). Further, no research to date has examined the differences in risk factor presentation between children referred for CSN funding and clinically referred children without CSN. To address the identified limitations, the current exploratory study included an examination of children who were referred by community agencies for CSN funding in Ontario. The current study utilized comprehensive assessment tools with strong psychometric properties. In addition, this study compared children who were referred for CSN funding to clinically referred children without CSN.

### **Study Aims**

This study had two main objectives. The first objective was to identify the risk factors that can assist in predicting CSN funding referrals by comparing children referred for CSN funding to clinically referred children without CSN. On the basis of previous research, we specifically examined whether children referred for additional support reported increased difficulties completing activities of daily living, mental illness comorbidity, physical/medical illness comorbidity, and impairments in family functioning (Burnside, 2012; Day et al., 2002; Department of Health, 2004; Hewitt-Taylor, 2005; Kennedy et al., 2007; Stewart-Brown & Schrader-McMillan, 2011; Teare, 2008; Vig et al., 2005). The second objective was to comment on the implications the findings may have for clinicians and policy makers in terms of identifying children most in need of additional funding. In order to meet these

objectives, this study utilized assessments from the interRAI Child and Youth Mental Health suite which are sensitive and comprehensive assessment tools that assess functioning, identify areas of need, and utilize multiple sources of information to assist with evidence-informed care planning (Stewart & Hirdes, 2015; Stewart, Hirdes, et al., 2015; Stewart, LaRose et al., 2015).

### **Hypotheses**

It was hypothesized that children referred by community agencies for CSN funding would present with reduced capacity for completing activities of daily living, increased physical/medical illness and mental health comorbidity, and more impairments in family functioning relative to children who were not referred for funding. Thus, it was expected that these risk factors would be able to predict CSN funding referral.

### **Method**

#### **Design**

This research project was a cross-sectional descriptive field study that examined risk factors among children referred for CSN funding. Secondary quantitative data collected across mental health agencies in the Province of Ontario was analyzed to identify relevant risk factors utilizing interRAI instruments.

#### **Participants**

The current study utilized a sample of 1020 male children who completed the interRAI Child and Youth Mental Health or Child (ChYMH) or Child and Youth Mental Health - Developmental Disability (ChYMH-DD) assessment between October 2012 and August 2015 across the province of Ontario. A majority of these participants completed the ChYMH or ChYMH-DD when seeking services at one of twenty mental health facilities as part of typical standard of care ( $N= 976$ ). A smaller subgroup was referred to the Ministry of Children and

Youth Services of Ontario by agencies across South Western Ontario for CSN funding. A specialized team then reviewed these referrals and completed the ChYMH or ChYMH-DD with these children/youth and their families ( $N= 44$ ).

The current study includes data collected from males between the ages of 4-18 years old (Male = 10.96,  $SD= 3.43$ ). Females were excluded due to ethical concerns around protecting child confidentiality (i.e., groups of less than 25 were not reported). All participants completed the assessments on a voluntary basis and their quality of care was not impacted if they choose not to complete the assessment.

### **Measures**

The two instruments that were utilized in this study were the ChYMH or the ChYMH-DD, which were created by interRAI, a not-for-profit collective of researchers and clinicians from over thirty countries. The ChYMH and ChYMH-DD are comprehensive instruments that incorporate information that would typically require multiple assessment tools (e.g., Stewart, Currie, Arbeau, Leschied, & Kerry, 2015; Stewart & Hirdes, 2015). Moreover, these instruments have been shown to have strong validity and reliability for adults, children, and youth (Carpenter, 2006; Gray et al., 2009; Hirdes et al., 2002; Hirdes et al., 2008; Phillips et al., 2011; Phillips et al., 2012; Poss et al., 2008; Stewart, Currie, et al., 2015; Stewart & Hirdes, 2015; Stewart, Klassen, & Tohvner, 2015a,b). The interRAI instruments are currently being utilized internationally across multiple settings to assess the strengths, needs and level of functioning of children, youth, and their families (Stewart, Hirdes, et al., 2015; Stewart, LaRose et al., 2015). In addition to providing service urgency algorithms to enhance triaging and prioritization, these instruments provide evidence-informed care planning based on need to promote efficient and effective clinical practice.



The ChYMH and ChYMH-DD instruments contain approximately 400 items that obtain information about the following areas: child/youth functioning, medical difficulties, social difficulty, psychiatric difficulty, environmental difficulty, information regarding strength and resilience as well as information regarding the family of the child or youth (Stewart, Hirde, et al., 2015; Stewart, LaRose, et al., 2015). The ChYMH-DD is designed for use with children who have intellectual and/or developmental disabilities. It is typically used with children who have intellectual and developmental concerns (e.g., autism) and whose intellectual functioning is under 70. When completing the ChYMH or ChYMH-DD, assessors obtain information by completing a semi-structured interview with the child and family/caregivers/guardians. In addition, information is also obtained through any other available sources including medical records and past/current service providers. Obtaining information from a variety of different sources provides additional support for the convergent validity of the information that is collected and promotes a more comprehensive understanding of the child's current levels of functioning, strengths and service needs. This information also assists with care planning of the child and supports service providers in meeting client needs.

The current study utilized a number different items and clinical presentation scales from the ChYMH and ChYMH-DD. These scales are designed to help provide a detailed understanding of the child's current clinical status and provide information regarding the issues the child and/or family may be struggling with, along with the frequency and intensity of those issues (higher scores suggesting increased severity/frequency of issues).

**Activities of Daily Living.** To assess for the presence of more severe neurological, developmental, or intellectual development disabilities that interfere with a child's adaptive functioning, the *Activities of Daily Living Scale* (ADL) was utilized. This scale assesses the child

or youth's ability to engage in a variety of different daily living tasks including: dressing, bathing, locomotion, etc. on a 6-point scale (0 = *independent* to 6 = *total dependence*).

Participants are scored on a scale of "0-48" with higher scores indicating greater dependency and decreased ability to independently perform activities of daily living. This scale has been found to have strong reliability and validity (Phillips & Hawes, 2015).

**Mental Illness Comorbidity.** For the purposes of this study, a mental illness comorbidity variable was created using items measuring different provisional DSM-IV diagnoses as indicated by a psychiatrist or physician. Items addressed a variety of common DSM disorders (e.g., autism spectrum disorder, adjustment disorders, and anxiety disorders). All of these items were initially recorded as 0 = *not present*, 1 = *most important*, 2 = *second most important*, 3 = *third most important*, 4 = *less important*, 8 = *no provisional diagnosis*. This data was then used to create a variable which was coded as: 0 = *no mental illness comorbidity* (if 0 or 1 DSM diagnosis was indicated) or 1 = *presence of mental illness comorbidity* (if 2 or more DSM diagnoses were indicated).

**Physical/Medical Illness Comorbidity.** For the purposes of this study, a physical/medical illness comorbidity variable was created using items on the instruments that inquired about previous medical diagnoses. These items measured a variety of common medical diagnoses (e.g., asthma, migraines, severe allergies). All of these items were initially recorded as 0 = *not present*, 1 = *primary diagnosis*, 2 = *diagnosis present and receiving active treatment*, or 3 = *diagnosis present but no active treatment provided*. This data was then used to create a variable that was coded as 0 = *no physical/medical comorbidity* (if 0 or 1 physical/medical diagnosis was indicated) or 1 = *presence of physical/medical comorbidity* (if 2 or more physical/medical diagnoses were indicated).

**Family Functioning.** The *Family Functioning Scale* (FFS) was utilized to evaluate family cohesion, conflict and hostility. The FFS also measures whether or not family members feel overwhelmed by the child's current condition or feel unable or unwilling to continue caring for the child. Additionally, information regarding the mental health status of the parents, siblings and other close family members is also measured. This scale is scored from 0-6 with higher scores being indicative of poorer family functioning. For the purposes of this study, this scale was treated dichotomously with scores of "0" indicating no difficulties in family functioning and scores greater than 0 indicating the presence of difficulties in family functioning.

### **Procedure**

The data collected using the ChYMH and ChYMH-DD was approved by the Western University Ethics Review Board (REB: 106415; see Appendix A). Data collected from participants was entered into a de-identified web-based software, password protected, encrypted, and stored on computers with no internet or USB ports to ensure confidentiality. This web-based software provided a randomly assigned, study-specific participant number. This de-identified data was then stored on a secure server at the University of Waterloo and was provided to the lead investigator of the project and interRAI fellow (Dr. Shannon Stewart) on a quarterly basis. Dr. Stewart was responsible for supervising all research that was conducted with this data.

The assessors who completed the assessments with the children included individuals from a variety of different disciplines including: nurses, psychologists, psychiatrists, social workers, child and youth workers, and speech and language therapists. Each assessor had completed a two-day training program prior to conducting the assessments. Assessors and participants completed either the interRAI ChYMH (Stewart, Hirdes, et al., 2015) or the interRAI ChYMH-DD (Stewart, LaRose, et al., 2015) assessment through a semi-structured

interview. The assessment took approximately 60-90 minutes for completion (depending on case complexity). To promote a thorough evaluation, the assessors were encouraged to complete the assessment with multiple informants including the child/youth, families/caregivers/guardians and any additional documentation (e.g., previous health records, education records) and collateral information (e.g., from teachers, psychologists) when possible.

### **Plan of Analysis**

To examine whether a set of risk factors (i.e., activities of daily living, mental illness comorbidity, physical/medical illness comorbidity, family functioning) could be used to predict CSN funding referral (0 = no funding referral, 1 = funding referral), binary logistic regression analyses were used. Binary logistic regression analyses are suitable for predicting dichotomous variables (i.e., CSN funding referral/no CSN funding referral) using a set of exploratory independent variables that can be categorical, continuous, or both (Field, 2013). Two logistic regressions were completed. First, it was examined whether the set of risk factors (i.e., activities of daily living, mental illness comorbidity, physical/medical illness comorbidity, family functioning) predicted CSN funding referral using the entire sample. Second, given that the sample size of the CSN group was disproportionately smaller than the non CSN group, we then ran an analysis using an aged and instrument type matched (ChYMH or ChYMH-DD) sample of non CSN cases (N = 44).

## **Results**

### **Preliminary Analyses**

Of the 1020 male children included in the study, 44 (4.31%) were referred by community agencies across Southwestern Ontario to be considered for complex special needs funding whereas 976 (95.79%) were not referred for CSN funding. Table 1 summarizes the age and type

of instrument utilized for participants in each of these two groups. Of the 976 participants not referred for funding, 961 (98%) presented with 0 or 1 physical/medical health illnesses and 14 (1%) presented with 2 or more whereas with the CSN group, 22 (50%) presented with 0 or 1 physical/medical health illnesses and 22 (50%) presented with 2 or more. With respect to mental illness comorbidity, 451 (46%) of the non CSN group presented with 0 or 1 mental health illnesses and 524 (54%) presented with 2 or more. 22 (50%) of the CSN group presented with 0 or 1 mental health illnesses and 22 (50%) presented with 2 or more.

Table 1

*Demographics of CSN funding and non CSN funding group*

	N (%)	ChYMH instrument (%)	ChYMH-DD instrument (%)	Age in years mean (± S.D.)
Non CSN	976 (95.69%)	824 (84.4)	152 (15.6)	10.88 (3.43)
Referred CSN	44 (4.31%)	18 (40.9)	26 (59.1)	12.86 (2.82)
Total	1020 (100%)	842 (82.5)	178 (17.5)	10.97 (3.43)

**Primary Analyses**

Binary logistic regression analyses were conducted to predict the presence/absence of a CSN funding referral using risk factors as predictors (challenges with activities of daily living, mental illness comorbidity, physical/medical illness comorbidity, and impairments in family functioning) for both the full sample and the matched sample. The full model provided a significantly better fit relative to the constant only model ( $\chi^2 = 29.886$ ,  $p < 0.01$ ,  $df = 4$ ; See Table 2) suggesting that the predictors reliability distinguished participants that were referred for CSN and those who were not referred for funding. Results indicated that of the 4 predictors,

impairments in family functioning and challenges with activities of daily living significantly predicted CSN funding referral. Mental illness comorbidity and physical/medical illness comorbidity were not significant predictors. These results were consistent with the matched sample ( $\chi^2 = 26.831$ ,  $p < 0.01$ ,  $df = 4$ ; See Table 3). See Table 2 and 3 for regression coefficients, Wald statistics, odds ratios and 95% confidence intervals for the reported odds ratios.

Table 2

*Logistic Regression Results for Complex Special Needs Funding and Risk Factors (full sample)*

Predictor	B	Wald	Odds Ratio (ExpB)	p value	95% Confidence Interval
Challenges with activities of daily living	0.058	10.504	1.060	0.001	[1.023-1.097]
Comorbid physical/medical illness	0.634	1.815	1.884	0.178	[0.750-4.737]
Comorbid mental illness	-0.340	1.118	0.712	0.290	[0.379-1.337]
Impairments in family functioning	1.802	8.674	6.065	0.003	[1.827-20.125]

Table 3

*Logistic Regression Results for Complex Special Needs Funding and Risk Factors (matched sample)*

Predictor	B	Wald	Odds Ratio (ExpB)	p value	95% Confidence Interval
Challenges with activities of daily living	0.106	5.676	1.112	0.017	[1.019-1.213]
Comorbid physical/medical illness	0.681	0.575	1.976	0.448	[0.340-11.490]
Comorbid mental illness	-0.592	1.300	0.553	0.254	[0.200-1.530]
Impairments in family functioning	2.297	10.106	9.945	0.001	[2.413-40.991]

### Discussion

Children with CSN present with multiple needs (e.g., physical, mental, social), require services across multiple sectors (i.e., home, education, mental health), and may require extensive funding to have their needs met (Abbott et al., 2005; Burnside 2012; Calvert & Lightfoot, 2002; McArthur & Faragher, 2014; Stewart & Hirdes, 2015). Although children with CSN represent the most challenging and most resource intensive children in clinical care (Bass et al., 2004; Calvert & Lightfoot, 2002; Clark et al., 2005; Teare, 2009), little research has examined the specific factors that distinguish children and families who seek additional services. Moreover, existing research on children who present with complex needs has been limited in a number of significant ways. For example, there have been inconsistencies around categorizing children with CSN and different terms and criteria have been used. Moreover, researchers have largely relied on narrowly focused (i.e., one domain) and limited assessments of children's complex needs (Carnaby, 2007; Clark et al., 2005; Spratt, 2010). Moreover, there is a need for policy makers to obtain an understanding of which risk factors in combination can predict children with the greatest need (i.e., children most likely to require extensive funding to have their needs met). To address these gaps in understanding, the current exploratory study examined risk factors present among children and families who are referred for complex special needs funding by utilizing comprehensive assessment tools. The purpose of this study was to identify the combination of risk factors that could distinguish families referred for complex special needs funding from those who were not referred for CSN funding.

On the basis of previous research reviewed on risk factors among children presenting with a great breadth and depth of needs, such as children with developmental disabilities, dual diagnoses, or multiple needs (e.g., Burnside, 2012; Clark et al., 2005; McArthur & Faragher,

2014; Tahhan et al., 2010), it was hypothesized that children referred for CSN funding would present with reduced capacity for completing activities of daily living, increased physical/medical illness comorbidity, increased mental illness comorbidity, and more impaired family functioning than children without CSN. As predicted, it was found that difficulties in completing activities of daily living and impairments in family functioning predicted funding referral; however, contrary to expectations physical/medical and mental illness comorbidity were not predictive of CSN funding referral in the present sample. This discussion will address: the relevance of these findings in the context of previous research, implications for practice and policy, limitations of the current project, and recommendations for future research.

**Challenges in Completing Activities of Daily Living.** The results suggest that difficulty in completing activities of daily living (e.g., toileting, bathing, eating) was a significant predictor of CSN funding referral such that families seeking funding were more likely to have children who had challenges completing activities of daily living independently. This finding is consistent with previous research of children with severe disabilities which found that these children present with significant deficits in adaptive functioning (Rosengard et al., 2007; Pastor et al., 2009; Roberts, & Lawton, 2001), and extends previous research by demonstrating that the most severe CSN cases (in which additional requests for support are sought) report even greater impairment in daily functioning than other high risk clinically referred children.

**Physical/Medical Illness and Mental Illness Comorbidity.** Contradictory to previous research which has suggested that the multiplicity of physical and mental health issues is the main characteristic that distinguishes CSN children (Burnside, 2012; Day et al., 2002; Hewitt-Taylor, 2005; Murray, 2003), the present study found that physical/medical illness and mental health comorbidity was not significantly predictive of CSN funding referral.



Historically, little attention has been given to psychopathology amongst children (Mash & Barkley, 2014). However more recently, knowledge about lifelong costs of childhood psychopathology has surfaced. Further, research has found evidence that suggests that many adult disorders originate in childhood (Mash & Barkley, 2014). These findings have sparked a great interest in childhood psychopathology and have led to an expansion of this literature. Despite these advances, symptoms of psychopathology present during childhood or adolescence do not result in diagnoses for many individuals until adulthood (Mash & Barkley, 2014). This is particularly true for children who may present with complexity; for example, studies examining children with intellectual disabilities have found that although these children are at a much higher risk for comorbid psychopathology, diagnoses of psychopathology prove challenging due to a variety of reasons (Cooper, Melville, & Einfeld, 2003; Costello & Bouras, 2006; Matson & Matson, 2015). First, differences in the presentation of psychopathology among children with intellectual disabilities relative to typically developing population have been noted, thus, assessments utilized to identify mental health needs in children with intellectual disabilities may need to be adapted to better reflect these differences. Second, clinicians have reported having to rely on reports from caregivers due to limitations children with intellectual disabilities have with respect to communication skills and articulating emotions. Relying on caregiver reports may result in the caregiver focusing on symptoms that prove the most challenging for them (e.g., inability of their child to complete activities of daily living). Finally, “diagnostic overshadowing” can occur in this population when symptoms that are indeed related to psychopathology are accidentally attributed to the child’s intellectual disability (Matson & Matson, 2015). Diagnostic overshadowing has also been known to take place amongst children with physical/medical health symptoms who present with behavioral and/or emotional disturbances in which psychological

symptoms are attributed to the child's medical condition instead of underlying psychopathology (Meltzer, Gatward, Goodman, & Ford, 2000). Moreover, when examining childhood psychopathology, researchers have also noted that many symptoms across disorders overlap with one another which further makes accurate and differential diagnoses difficult (Angold, Costello, & Erkanli, 1999). These factors, in tandem, may have contributed to an underestimation of the prevalence of comorbid psychopathology amongst children referred for CSN funding.

Another possible explanation for this unexpected finding is that since all participants included in the current study were seeking mental health services, the study comprised of a highly clinical sample with high rates of mental health illnesses. As is evident from the results, mental health comorbidity rates appeared similar across the CSN and non CSN groups such that it was not a distinguishing feature of CSN funding cases. This is further supported by literature which suggests that mental health disorders tend to occur simultaneously in childhood (e.g., mood and anxiety disorders; Merikangas, Nakamura, & Kessler, 2009).

**Family Functioning.** In the present study, it also was found that impairment in family functioning was a significant predictor of families referred for CSN funding. Families applying for funding were more likely to have impairments in family relationships, exhibit hostility toward the child, express feelings of being overwhelmed by the child's condition, or indicated the unwillingness or inability to continue caring for the child. These families also were more likely to have other family members (i.e., parents or siblings) with developmental disabilities, mental health concerns, and/or substance use issues, relative to a clinical population not applying for funding.

The results of the present study are consistent with previous literature that suggests that family dysfunction can be predictive of poor outcomes amongst children with complex needs

(e.g., Hewitt-Taylor, 2005; Landy & Tam, 1998; McArthur & Faragher, 2014). More specifically, previous literature has indicated that the parent's health condition (i.e., mental illness/disabilities, physical/medical illness, substance use) may lead to greater risk for insecure attachment, psychosomatic issues, difficulties in psycho-emotional development, and increased psychopathology among children (Burke, 2003; Cleaver et al., 2011; Cummings & Davies, 1994; Faller, 2000; Goodman et al., 2011; Preyde et al., 2011; Tunnard, 2004). Additionally, parent's personal mental health difficulties can impact their ability to: be involved in their child's treatment, obtain support for their child's development, and process the information regarding their child's condition and needs (Head & Abbeduto, 2007; Preyde et al., 2011). Further, for parents with pre-existing mental health concerns, there appears to be greater rates of reported "parental burden" experienced due to their child's psychiatric disorders relative to parents without mental health concerns (Angold et al., 1998). Moreover, parent's feelings regarding parental competency is also known to be associated with internalizing and externalizing symptoms among children with mental health concerns (Preyde et al., 2015). Additionally, parents who present with disabilities have known to experience higher rates of divorce or separation (Human Resource and Skill Development Canada, 2006) which may contribute even further to feelings of being overwhelmed and/or incompetent in caring for their child with complex needs. These aforementioned factors can, in combination, create further difficulties for families already presenting with complexity.

It is also possible that the multiplicity of needs the child presents with contributes to the emotional and behavioral difficulties experienced by parents as these parents have noted feeling burdened and stressed due to increased emotional, physical, and financial responsibility (Hewitt-Taylor, 2005; McArthur & Faragher, 2014; Preyde et al., 2015; Reid et al., 2011; Robinson et al.,

2001). Feeling burdened and overwhelmed by the child's care needs, may impact the degree of attachment between the child and his/her caregiver as well as the overall functioning and relationships within the family. It is important to note that the current study did not examine the direction of the relationship between individual familial factors (e.g., parent's mental health status) and CSN funding. However, it is likely that multiple familial factors work in combination to impact the family's functioning and need for additional funding.

Taken together, the most critical finding of the current study is that a large percentage of clinically referred children in the present study experienced physical and mental health concerns. However, families of children seeking CSN funding presented with children who experienced significantly more challenges in completing activities of daily living (i.e., children required additional support for basic daily tasks such as feeding and dressing) and experienced higher levels of family dysfunction than families without children with CSN. It is possible that deficits in adaptive functioning amongst children with CSN may lead to family members experiencing increased pressure to be available for their child on a daily basis (Contact a Family, 2011; Kilic et al., 2013; Teare, 2008). Indeed, the demands placed on the family of a child with CSN may result in high levels of physical and psychological stress, as well as financial burden. On the other hand, if parents present with health conditions (e.g., mental health, disabilities, and substance use issues), they may be less likely to be available to address their child's needs, feel competent in caring for their child, familiarize themselves with resources that may be of assistance to the child, participate in their child's treatment and may experience greater degrees of perceived burden (Angold et al., 1998; Head & Abbeduto, 2007; Preyde et al., 2011). This can further limit the opportunities the child is provided with to develop skills that may help him/her become more independent with respect to daily living. Moreover, when parental functioning is

compromised, the entire family has known to be affected due to the impact parental functioning has on parenting, parent-child interactions, and childhood psychopathology (Hauser-Cram et al., 2001; Luthar, 2003; Mink and Nihira, 1986). It is important to note that due to the cross sectional nature of the study, the study does not provide information with respect to the direction of the relationship between impairments in family functioning and challenges in completing activities of daily living and how these influence the families need for funding. The findings do, however, indicate the combination of risk factors (i.e., impairments in family functioning and challenges in completing activities of daily living) that profile children who are at the greatest risk for additional financial support.

### **Implications for Practice**

Important implications for clinical practice, assessments, and treatment planning can be derived from the present study. When working with children with complex needs, it is necessary for clinicians to obtain a comprehensive understanding of the risk factors with which both the child and family present, and more importantly, obtain an understanding of the combination of risk factors that may be impacting the family unit and contributing to the need for additional funding. The current study demonstrates that single risk factors, although important on their own, need to be taken into account with other factors that are impacting the child and family. More specifically, when discussing children with complex special needs, attention needs to be drawn towards the functioning of the family and how the family is impacted by the child's adaptive functioning (or vice versa).

Assessments of children with CSN should examine the child's ability to independently complete activities of daily living (e.g., bathing, toileting, dressing) and how impairments in this area may be impacting the family unit. For example, if the child is unable to complete activities

of daily living, how is the family able to meet these needs? Do parents need to take time off work or reduce work hours in order to provide supervision and assistance to their children? Do parents have the capability to meet the needs of their children independently? If not, do parents have access to additional supports that can help them meet the needs of their children? If not, what does this mean for the family unit? On the other hand, clinicians also need to assess whether existing family factors (e.g., parental mental health, substance abuse, etc.) may be impacting the child's ability to develop daily living skills.

Traditionally, when completing assessments, clinicians have utilized assessments that are "child focused" in order to identify the child's needs, any relevant diagnoses, provide recommendations for treatment and finally, to evaluate progress (Head & Abbeduto, 2007). However, the findings of the current study point to the importance of considering factors that extend beyond just the child's presentation. More specifically, the results of the present study underscore the need for utilizing assessments that are more comprehensive and that consider the entire family unit, as children cannot be viewed as separate from their families and thus services should not be provided without taking family contexts into account (Bailey, Raspa, & Fox, 2012; Preyde et al., 2011; Preyde et al., 2015). One approach to such an assessment is one that takes a systems approach rather than one solely focused on child's needs (see Head & Abbeduto, 2007). With this approach, the "patient" is not the child but the entire family system and thus, assessments are completed with consideration of the needs, challenges, and strengths all of the individuals that make up the family unit (e.g., child, parents, and siblings). Doing such an assessment involves a variety of different components including building rapport with each family member, evaluating the family context (e.g., coping mechanisms), assessing the psychological wellbeing (e.g., stress levels) of family members and considering the family

environment (e.g., interactions between family members; Head & Abbeduto, 2007). Completing a comprehensive assessment that examines various areas of risk and identifies areas of need for the child and family, as reflected in the ChYMH or ChYMH-DD, will be beneficial in creating treatment plans that are targeted, holistic, and that consider the family unit thereby, promoting family cohesion and positive family functioning which have known to have positive impacts on adaptive functioning, behavior outcomes, and social and emotional development amongst children with mental health concerns and/or disabilities (Hauser-Cramer et al., 1999; Hauser-Cramer et al., 2001; Mink & Nihira, 1986, Preyde et al., 2015).

After completing thorough assessments, it is imperative that clinicians utilize the gathered information to create treatment plans that consider the needs of the entire family as they relate to the child's functioning as family functioning and family relationships can play an important role in treatment considerations and treatment outcomes (Preyde et al., 2011; Sunseri, 2004). When possible, these treatment plans should account for the family's ability and feelings of competency in participating in treatment as well as in seeking out recommended resources and referrals (Head & Abbeduto, 2007; Evans, Sibley, & Serpell, 2009; Preyde et al., 2015). A recent study conducted by Preyde et al., (2015) examined the relationship between adolescent mental health (of adolescents in residential treatment care or intensive home based treatment) and parental competency. From their study, it is suggested that parents of these youth reported feelings of incompetency with respect to caring for their children. These feelings of inadequacy and feeling unable to manage their child's behaviour likely play an important role in families' decisions to seek additional assistance (e.g., out of home care; Preyde et al., 2015; Tahhan et al., 2010). Feelings of incompetency have shown to be related to family functioning and family quality of life (Evans et al., 2009; Preyde et al., 2015). Families of children in out of home

placements report a desire to obtain increased knowledge about their child's behavior and how to manage it (e.g., Tahhan et al., 2010) and thus, treatment plans should consider the families' needs and target parenting skills to enhance the competency felt by these parents and overall family functioning. When possible, efforts should be made to include family members and guardians in treatment delivery and identify factors that may either help to promote or interfere with positive outcomes early on (Affronti & Levinson-Johnson, 2009). In addition, family therapy and psycho-education for family members should be incorporated, when possible (Affronti & Levinson-Johnson, 2009; Sunseri, 2004).

Overall, it is apparent that family functioning and family factors play an important role in distinguishing families requiring additional resources (e.g., additional funding, out of home placements) and thus, the family unit should be considered in the assessment and treatment process to promote positive outcomes and reduce service system burden. Consideration of the whole family unit and how risk factors are in combination affecting the family will also provide clinicians with a better understanding to make informed decision about which families require the most resources. Additionally, assessments completed with these families should be standardized and streamlined when possible, as families of children with complex needs have noted their feelings of frustration when having to re-tell their story to various service providers (Rankin & Regan, 2004). The information in these assessments should be shared among professionals involved in the care of the child to promote continuity in care.

### **Implications for Policy**

When making decisions about which clinically referred children should be eligible for CSN funding, it is essential that policy makers are obtaining a comprehensive understanding of each family and their presenting concerns. This requires the inclusion of comprehensive



assessment tools (e.g., interRAI instruments) to be integrated into decision making processes, to allow key stakeholders to better understand the risk factors that are present, the range of services that are required, as well as the degree of complexity that is involved in each case so that informed decisions can be made regarding which families are most in need of additional funding. Comprehensive assessments would also allow for policy makers to identify targeted services and interventions that would be most beneficial to the family unit.

### **Limitations**

The findings of this study need to be taken into account within the context of its limitations. First, due to reporting restrictions for groups under 25, this study was limited to only males. It is possible that males and females applying for CSN funding present with different risk factors and thus, future studies should incorporate both sexes where possible. Second, as previously stated, the sample consisted of a convenience sample of children seeking mental health services across the province of Ontario. Moreover, the children referred for CSN funding were referred using the criterion outlined by Ontario guidelines for CSN funding. This limits the generalizability of the study, as this convenience sample may not be representative of the broader population of children with CSN who may seek funding elsewhere. Moreover, the small sample size of children referred for CSN funding limits the statistical power and generalizability of the findings amongst the broader population of children with complex special needs. Finally, the current study examined the risk factors that appeared to be the most prominent in the literature of children with a great breadth and depth of need. Due to limitations with sample size, the current study was limited with respect to the number of risk factors that could be examined and thus, every risk factor previously discussed in the literature was not examined.

### **Recommendations for Future Research**

Future research should attempt to replicate the findings of this study using a larger sample that includes both males and females and that includes children referred for CSN funding across various provinces in Canada. This would help provide a more comprehensive understanding of the risk factors present amongst vulnerable children seeking funding. This would also allow researchers to examine a broader number of risk factors that may impact CSN presentation. Future studies should also examine additional factors that may be associated with funding referral (e.g., socio-demographic status, location of family in relation to location of services needed; See Cantwell, Muldoon, & Gallagher, 2014; Farmer, Clark, Sherman, Marien, & Selva, 2005; Thurston, Paul, Loney, Wong, & Browne, 2011) that were not address in the current study. This would would help to provide a more thorough understanding of additional factors that may play a role in families needing to apply for funding. For example, it may be the case that children who have complex needs who are located in a rural area are more likely to be referred for funding due to extra costs associated with obtaining services (e.g., cost of flights) relative to children with complex needs in urban areas.

Future research should also examine the personal experiences of families and children with complex special needs. More specifically, investigating the types of services these family are seeking funding for, the areas in which their needs are not being met, as well their experiences with obtaining community services. A study of this nature would allow for a more in-depth understanding of the needs and challenges of these families and provide knowledge regarding the types of services that are current lacking or require improvement thereby informing service delivery.

Future studies should also examine the service utilization patterns of children and families referred for CSN funding. It is likely that families of children with CSN may be seeking extensive funding to obtain assistance in helping their children complete activities of daily living, such as feeding, bathing, and dressing. Previous research has found that families of children with CSN have communicated the challenges they face with respect to finding professionals who are suitable (and affordable) to meet the needs of their children (Carnaby, 2007; Cohen et al., 2011); thus, it follows that families may be seeking funding to be able to afford professionals that have specialized training and who are better suited to meet the needs of their child. Moreover, the services being sought are likely intensive, one on one services that would allow opportunities for the child to be assisted and supervised at all times. An examination of service utilization would provide clinicians and policy makers with more in depth information about the types of services that are being sought and the steps that need to be taken to promote the positive outcomes for the child and family unit.

Future studies may also benefit from examining the factors that promote resiliency among families of children with complex needs. For example, examining what factors distinguish families of children with complex needs seeking funding from those who are able to thrive despite similar adverse circumstances without additional assistance. Previous research has demonstrated the impact that protective factors (e.g., social support, parental sense of competency, etc.) can have on outcomes for children who experience adverse life circumstances and families have articulated their desire for service providers to focus on the strengths of the child and family (Anguilar-Vafaie, 2011; Jones & Prinz, 2005; Kim-Cohen, 2007; Lee Cheung, & Kwong, 2012; Walker et al., 2011). For example, social support has known to directly and indirectly impact family well-being, quality of parenting as well as resiliency among children

and has overall been identified as a protective factor in face of vulnerability (Armstrong, Birnie-Lefcovitch, & Ungar, 2005; Saewyc, 2006; White & Hastings, 2004). Examining protective factors present amongst families of children with CSN would be essential in implementing treatment programs that incorporate strengths and promote positive outcomes for families presenting with multiple risks.

### **Summary**

Despite the aforementioned limitations, the current study provides critical information regarding families seeking additional funding for their child(ren)'s complex special needs. By examining children seeking funding for CSN, a combination of risk factors that distinguished families seeking funding were identified. Findings suggest that although many clinically referred children present with physical/medical and mental health problems, children and their families applying for complex special needs funding present with significantly more impairments in completing activities of daily living and family functioning. These results provide clinicians and policy makers with a better understanding of the unique characteristics present amongst this population as well as information about treatment considerations and service provision.

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## Appendix A



Western  
Research

Research Ethics

Western University Health Science Research Ethics Board  
HSREB Delegated Initial Approval Notice

**Principal Investigator:** Dr. Shannon Stewart  
**Department & Institution:** Education\Faculty of Education, Western University

**HSREB File Number:** 106415  
**Study Title:** Secondary data analysis of information collected using interRAI instruments  
**Sponsor:**

**HSREB Initial Approval Date:** March 31, 2015  
**HSREB Expiry Date:** March 31, 2016

**Documents Approved and/or Received for Information:**

Document Name	Comments	Version Date
Western University Protocol	Received Mar.11/15	

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

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