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Exploring the Impacts of Learning Challenges for Children Not Yet Identified with a Learning Disability

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Abstract

Significant learning challenges can manifest years before children are often eligible to be diagnosed with a Learning Disability (LD). Without a formal diagnosis, many children are often limited in the resources and supports that may receive and critical opportunities for early intervention are missed. This study sought to understand and assess the impact of learning challenges experienced by school-aged children (Grades 1 to 9) who had not yet formally received a diagnosis. Ten parents were recruited from London, Ontario and its surroundings counties (Elgin, Middlesex, Oxford) who were caring for children with significant learning challenges. Data were collected using a combination of quantitative and qualitative methodology. Study participants completed a range of standardized measures to assess the severity of children's challenges across academic, behavioural, socio-emotional and familial domains. A semi-structured interview was also used to explore parent's caregiving experiences and perceptions of self-determination.

Descriptive data indicated that children and their families were significantly impacted by learning challenges notwithstanding formal diagnostic recognition of their challenges.

Qualitative content analysis revealed three overarching themes. These included parent's knowledge and understanding of children's learning challenges, prominent caregiving needs and available supports. Parents perceptions supported the concept of self-determination as illustrated by specific behaviors of children in this sample. Results highlight continued areas of improvement in how supports are provided for children with learning challenges across school, community, and professional services.

Keywords: Learning Disabilities, Early-Intervention, Caregiving, Mental Health, Self-Determination

Lay Summary

Children are impacted by learning challenges years before they can be diagnosed with a Learning Disability (LD). In many provinces, an official LD diagnosis is required to be considered eligible for various supports and services. This study will demonstrate the experiences of school-aged children (Grades 1 to 9) with learning challenges and their families before receiving a formal diagnosis. We recruited 10 families from London, Ontario and its surrounding counties (Elgin, Oxford and Middlesex) to participate. Study participants completed a series of questionnaires and took part in a short interview. Questionnaires measured parent's perceptions of the impact of their child's learning challenges on academic, behavioural, social, emotional, and familial domains. The interview explores parent's views on caregiving children impacted by learning challenges. We asked questions about their child's everyday caregiving needs, parent's knowledge and understanding of learning challenges, parent's main concerns in caregiving, and their child's supports. We also asked parents to discuss behaviours that show their child is able to act independently. Our results show the effects that learning challenges have on children and their families, and highlights areas where supports could improve to better meet the needs of children impacted by learning challenges and their families.

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Introduction

According to the Learning Disabilities Association of Canada (LDAC), Learning Disabilities (LD) represent a category of genetic and/or neurological disorders affecting cognitive processes (e.g. executive functions, processing speed, memory) associated with the acquisition, retention, and understanding or use of verbal/non-verbal information despite the child having average abilities in thinking and/or reasoning (Official Definition of Learning Disabilities, 2015).

In early childhood, LD are expressed through marked deficiencies in reading, writing, spelling, and mathematics capabilities (Balikci & Melekoglu, 2020). Regarded as a life-long condition (Official Definition of Learning Disabilities, 2015), the LDAC advocates early intervention as essential to promote adaptive functioning in individuals with learning challenges. The importance of timely supports was demonstrated in the ground-breaking study, “Putting a Canadian Face on Learning Disabilities (PACFOLD)” (Wilson, Furrie, Walcot-Gayda, Armstrong, & Archer, 2007) that involved 10 nationwide surveys conducted between 1991 and 2002. This study demonstrated that young adults (15-29) and adults (30-44) with LD are significantly more likely to drop out of school, be unemployed or underemployed, remain living with a parent or caregiver, and report fair or poor mental health in the absence of adequate support. As such, the impacts of LD extend well beyond academics, and can have pronounced limitations for Canadian citizens in areas of work, education, family life and physical and emotional health.

According to the Ontario Ministry of Education, many specialized or intensive remediation programs across Ontario schoolboards may require formal identification of a LD or a formal educational exceptionality (Special Education in Ontario: The Individual

Education Plan, 2017) for specific forms of support to be provided. Given the challenges, however, with staffing of professionals who are qualified to provide a formal diagnosis or support a formal educational exceptionality (e.g., Psychologists; Speech and Language Pathologists), along with long wait-lists for formal assessment, diagnosis may be deferred for years after children at risk of LD are first recognized. Furthermore, supports are often intended to eliminate academic challenges associated with LD so as to help children attain minimal standards of achievement (Wilson, Furrie, Walcot-Gayda, Armstrong, & Archer, 2007) . However, the impairments and effects of LD often extend beyond academic performance.

Approximately 30% of children and youth with LD will experience other neuropsychopathological conditions, including: Attention-Deficit/Hyperactivity Disorder (ADHD); Major Depressive Disorder (MDD); and Anxiety Disorders (Sahoo, Biswas, & Padhy, 2015). Despite the high co-occurrence between LD and other neuropsychological disorders, service provision policies focus mostly on remediation of academic under-achievement (D'Intino, 2017) to the relative exclusion of socio-emotional and behavioural deficits. Furthermore, clinical treatment and educational supports often neglects the needs and context of the family, despite the family unit being an essential aspect of children's development (Crnic, Gaze, & Hoffman, 2005). These findings are in line with survey data collected from Canadian families demonstrating an insufficient number of specialized mental health services available for families of children with learning challenges (Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007).

Despite a growing awareness of the barriers to support for children with LD, there have been few studies exploring the needs of children whose learning challenges have not

been formally recognized. The current study is a first exploration into parent's perceptions of needs associated with managing children's learning challenges prediagnosis, as well as the adequacy of available services and supports to address those needs.

Conceptual Framework

Since its conception, disability studies have undergone countless revisions. Building upon its predecessors, contemporary models of disability now envision/advocate a model that enables persons with disabilities to enact their inborn rights to dignity and autonomy; often characterized as a human-rights approach (Stein, 2017). Two models – the medical model and social model – have proven particularly influential in shaping the human-rights model of disability, and continue to guide public perception, politics and clinical practice concerning disablement. The following section highlights how each of these models contribute to modern conceptions of LD as well as their implications for the present study.

Medical Model

The medical model defines disability as an intrapersonal impairment, indicative of deviations from “normal” bodily functioning. From this perspective, the identity of persons with disabilities are inextricable from their supposed “defect”, thus creating a dichotomy between persons with disabilities and “normal” or “able bodied” persons (Degener, 2016). This categorical framework assumes that persons with disabilities depend upon available services and supports – this being a natural consequence of inherent limitations that confine their capacity to perform certain social functions (Stein, 2017). Accordingly, persons with disabilities are presumed subordinates to medical

professionals/government bodies overseeing their treatment; thus forcing them to resign their right to actively participate in political or cultural life (Degener, 2016).

Nevertheless, the medical model had important implications in understanding the underlying biological and psychological factors contributing to learning challenges. Research following in this tradition emphasized the measurement of impairment through normative referencing, which would aid in delineating distinct diagnostic categories related to LD (Berghs, Atkin, Graham, Hatton, & Thomas, 2016). As such, the medical model helped advance knowledge about the neuropsychological and neurobiological features of LD and continues to inform educational intervention efforts catered to this population (Gartland & Strosnider, 2018). Where this model falters is its ignorance of factors external to individuals with learning challenges, such as larger social systems and structures that interfere with their ability to function adequately. Hence, scholars argued for a social model of “disability”.

Social Model

The social model defines disability as a social phenomenon that systematically oppresses people with learning challenges (Degener, 2016). A sociological perspective argues that disabilities are embedded within social contexts, in that they are characterized by a discrepancy between the abilities of the individual, and the expectations or demands of the social group within which that person resides (Anastasiou & Kauffman, 2013). This perspective recast disability as societies’ response to the continuum of human variation (Degener, 2016). As such, disability studies espousing a sociological-perspective concentrate on factors of social organizations (and institutions) that limit

persons with learning disabilities from fully participating in meaningful activities and tasks, such as expressing knowledge, competencies, skills and abilities (Degener, 2016).

However, by focusing exclusively on social processes, this model neglects the neurobiological and neuropsychological correlates of LD, and ignores the reality of individual challenges often resulting from these cognitive, emotional, and social differences (Anastasiou & Kauffman, 2013). Furthermore, isolating social factors also negates the interactive relationship between biology and society, contrasting now prevailing beliefs that understanding disability must give consideration to both biological differences and social context (Anastasiou & Kauffman, 2013).

Human Right Model

Many of the aforementioned criticisms are addressed explicitly through alternative approaches to disability studies. Most notably are models conceptualizing disability using rights-based approaches. Predicated on the United Nations Convention on the Right of Persons with Disabilities (CRPD), the human-rights model represents efforts to guide disability policy – “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” (UN Convention on the rights of people with disabilities and optional protocol, 2006).

Whereas the social model ignores the association between impairment and life circumstances (e.g. reduced quality of life, dependency), the human rights model demands such limitations be considered when developing disability policy. Indeed, CRPD guidelines espouse “respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.” (UN Convention on the rights of

people with disabilities and optional protocol, 2006) and thus acknowledges impairment as a component of human variability. In this regard, removing barriers is necessary, but not sufficient alone to empowering persons with disabilities; it is necessary also to provide supports that would enable human-rights holders to function adequately in spite of their limitations. (Ward & Stewart, 2008) Therefore, disability studies must also consider the extent to which environments enable normalization; that is, the right to access and ability to live one's life. Importantly, our use of the term normalization is not intended to support the notion that disability is socially unacceptable (Yates, Dyson, & Hiles, 2008). Within this context, normalization refers to enabling individuation and respecting choice, and not conformity.

Taken together, a human-rights perspective to the study of LD must: (a) recognize variations in ability; (b) acknowledge barriers generated by disability discourse; and (c) offer solutions to empowering individuals with LD as human-rights beneficiaries.

Keeping in line with a human-rights approach, our review of relevant literature will: characterize learning challenges in relation to co-occurring academic, behavioural, socio-emotional and familial challenges and introduce ways in which families, educators, and professionals might empower children with learning challenges to overcome systemic barriers in their environment.

Defining Learning Disabilities

Most Canadian provinces characterize LD through IQ-achievement discrepancies (D'Intino, 2017). According to the discrepancy model, eligibility for LD status requires: (a) a noticeable discrepancy between intellectual/cognitive functioning and academic underachievement in one or more academic domains (e.g. reading, writing, mathematics);

(b) a cognitive or psychological processing deficit; (c) evidence that the child's educational needs necessarily require special instruction or related supports; and (d) that the discrepancy could not be explained through extraneous factors (e.g. by hearing/vision problems, socio-economic factors, cultural or linguistic factors, etc.; Restori, Katz, & Lee, 2009). Despite being profoundly implicated in determining eligibility for Special Education services, there is mounting evidence contradicting IQ-achievement discrepancy as a standard of LD identification.

Several critiques appear relevant to the current study. Firstly, evidence suggests that intelligence alone only moderately predicts academic performance (Ohtani & Hisasaka, 2018). Indeed, researchers have shown that having average intelligence is sufficient for developing a range of skills and cognitions (e.g. phonological awareness) necessary for students to successfully participate and perform adequately in a range of academic domains (Vellutino, et al., 1996; Lovett, et al., 2017). Secondly, overreliance on IQ-achievement discrepancy encourages a “wait-to-fail” approach to LD identification, whereby early-elementary school children experiencing (legitimate) academic difficulties must demonstrate a consistently low level of achievement over several years to meet eligibility criteria for LD (Restori, Katz, & Lee, 2009). For some time, researchers/practitioners have posited that children at-risk of later academic difficulties could be accurately diagnosed by 1st grade (age 6) (Gresham, 2002). Indeed, researchers have demonstrated that intervention programs can be equally effective at improving academic performance when implemented in 1st (and subsequent) grade(s) (Lovett, et al., 2017). Consequently, children subjected to a discrepancy model of LD identification lose years of skill development and valuable instructional time. Lastly, as

mentioned previously, a categorical-approach that differentiates children with and without LD based on an arbitrary cut-off points (Restori, Katz, & Lee, 2009) undermines the heterogeneity that exists amongst children who struggle in their academics. Although researchers have demonstrated some degree of overlap regarding genetic, developmental, and cognitive factors (Tannock R. , 2013), further investigations have revealed that there is considerably more discrepancies than similarities both across and within LD sub-types (Poletti, Carretta, Bonvicini, & Giorgi-Rossi, 2018)

The advent of the term “Specific Learning Disabilities” (SLD) contributed to a new appreciation for the specificity and diversity in abilities amongst children with learning challenges. According to Kavale and Forness (2000), the term “specific” signifies how learning challenges emanate from a *limited* number of cognitive skills resulting in unexpected academic underachievement *and* a profile of unique cognitive assets. This shift in conceptualizing LD is illustrated by reauthorizations in the Individuals with Disabilities Education Act in 2004 (Kozey & Siegel, 2008), which permits alternatives to IQ-achievement discrepancies for the identification of LD.

Since IDEA reauthorizations, “best practice” recommendations for screening, identification, and intervention of SLDs in Ontario have given prominence to advantages/disadvantages of alternative models (Harrison, 2007). In general, researchers and professionals support comprehensive evaluations that incorporate components of the Responsiveness-to-Intervention (RtI) and Patterns of Strengths and Weaknesses (PSW) frameworks. RtI refers to “a process that determines if a child responds to research-based intervention as part of the evaluation procedures” (Individuals with Disabilities Education Act, 2004). The RtI model identifies students “at-risk” of academic failure, and delivers

tiered instruction/intervention suited to the intensity of support needs assigned to individual students (determined through continuous progress monitoring) (Kranzler, Gilbert, Robert, Floyd, & Benson, 2019). Despite its advantage as a model of prevention (Mather & Tanner, 2014), using RTI to conceptualize LD makes it challenging to identify *why* (i.e. underlying cognitive deficits) specific children experience academic struggles (Kranzler et al., 2019). Accordingly, students who fail to benefit from “appropriate” remedial interventions are (at times) provided in-depth assessments to identify patterns of cognitive-processing strengths and weaknesses (Harrison, 2007). In spite of critiques challenging its use for identification purposes (McGill & Busse, 2017; Kranzler, Gilbert, Robert, Floyd, & Benson, 2019), researchers (and practitioners) maintain that identifying impairments (and strengths) in specific psychological processes can complement recommendations for specialized home, school, and community supports. Further, such procedures are especially relevant to children who do not show improvements through tiered intervention (Flanagan D. P., Ortiz, Alfonso, & Dynda, 2006; Harrison, 2007; Rosenblum, Larochette, Harrison, & Armstrong, 2010; Fiorello, Flanagan, & Hale, 2014). As such, the following discussion of academic strengths and weaknesses is focused on literature emanating from a PSW approach. Although there are several distinct methods of applying the PSW model to LD identification, most appear to follow similar guidelines: identifying academic needs; linking academic needs to cognitive processing deficits; identifying cognitive strengths; and comparing the resulting pattern to profiles of specific learning disabilities (SLD) (Schultz, Simpson, & Lynch, 2012). Within this approach, given the paucity of literature that regards learning challenges as a pattern of strengths and weaknesses, alternative literature at times is consulted.

Academic Performance

Literature concerning academic performance was divided by category – reading, math, and writing - to help delineate unique cognitive processing deficits and assets uniquely associated with groups of learning challenges. The authors acknowledge several discrepancies regarding their classification of cognitive-processing strengths and weaknesses within/between learning disability subtypes that appeared in their review of literature. This phenomenon is likely attributed to weak consensus in PSW assessment procedures (McGill & Busse, 2017). Notwithstanding such dissonance, the following review will provide insights into the nature of learning challenges across academic domains for children within the current sample.

Reading Disabilities

Reading Disabilities (RD) (or Dyslexia) refer to categories of oral-language processing deficits resulting in difficulties decoding and/or comprehending written text (Hulme & Snowling, 2016). A meta-analysis of 32 studies exploring 11 cognitive processing and achievement categories revealed that RD is uniquely associated with weaknesses in response inhibition, working memory, set-shifting, planning, vigilance, fluency, interference control, response variability and processing speed (Johnson et al., 2010). Using a similar methodology, Willcutt et al. (2010) showed that RD is distinctively related to poor phonological decoding, verbal reasoning, working memory, naming speed, and processing speed. These results have been replicated across multiple research articles (e.g. Johnson et al., 2010; Swanson & Jerman, 2006; Kearns, 2010). In a similar fashion, researchers have identified naming speed (Swanson & Jerman, 2006) and

visual spatial working memory (Swanson & Jerman, 2006; Kearns, 2010; Everatt, Weeks, & Brooks, 2008) as unique strengths associated with children with RD.

Compton et al. (2012) expanded this body of literature through delineating RD by academic outcomes to explore patterns of cognitive and academic strengths and weaknesses associated with unique word reading (i.e. decoding) and reading comprehension challenges. Findings suggests reading comprehension LD results from poor language skills – a composite of listening comprehension, oral vocabulary, and syntax – while word reading LD results from poor oral vocabulary and working memory. Interestingly, both RD subtypes (as well as applied-problems LD) display relative strength in processing speed when compared to children without LD.

Math Disabilities

Math Disability (MD) (or Dyscalculia) is characterized by difficulties involving numerosity and arithmetic. Researchers have proposed that MD, similarly to RD, represents a heterogenous group differing mostly by a unique association to distinct cognitive deficits; skills such as semantic memory retrieval, procedural memory, and visual-spatial memory (Geary, 2003). However, researchers seldom make this distinction, treating MD as a homogenous group having cognitive processing strengths and weaknesses (somewhat) distinct from other specific learning challenges.

Leading research efforts, Swanson et al. (2006) conducted a meta-analysis of 28 studies comparing children with MD to “average achievers”, children with RD, and children with co-morbid MD and RD across 17 categories representing various cognitions. Relative to controls and children with RD, children with MD evidenced mild-to-moderately poorer performance in measures of verbal problem solving, naming speed,

visual-spatial working memory and long-term memory. Johnson et al.'s (2010) led a similar review of 9 studies comparing children with MD to typically achieving students and found moderate-to-large discrepancies in executive functioning, processing speed, and short-term memory (which includes recall of digits, words, and sentences) in favour of typically achieving students. Others have noted MD may also be associated with cognitive weaknesses in verbal-comprehension (Willcutt, et al., 2013), set-shifting (Willcutt, et al., 2013), and numerosity (i.e. the ability to count or order sequences, use place value, and identify fractions, percentages and decimals; Bartelet, Ansari, Vaessen, & Blomert, 2014). Regarding strengths, Swanson et al. (2006) identified moderate effect-sizes in favor of MD on measures of literacy, visual spatial problem solving, and verbal working memory. Likewise, though less compelling, Andersson (2010) observed that performance on tasks requiring phonological retrieval, semantic retrieval, and verbal working memory was comparable between children with MD and controls (i.e. average achieving students).

Spelling or Writing Disabilities

Spelling Disability (SD) (or Dysgraphia) is characterized by impaired letter/number writing and fine-motor skills. Similarly to MD, there is a paucity of literature evaluating disorders of written expression in isolation. These circumstance are perhaps due to high comorbidity rates with other SLDs (i.e. RD and MD) (approximately 75%: Mather & Wendling, 2011), which encourage researchers to analyze SD and RD together as a homogenous group (McCabe, 2019). Alternatively, this may result from perceptions that written expression in education is not *as* significant relative to reading and math ability (Mather & Wendling, 2011).

A recent study by McCabe (2019) found (somewhat) distinct cognitive profiles between groups with specific learning disorder in reading (SLD-R) and comorbid reading and writing disorder (SLD-RW). Although groups presented with similar processing strengths and weaknesses, individuals with SLD-RW were less likely to demonstrate visual spatial reasoning deficits compared to individuals with SLD-R (4.5% versus 13.3%), and more likely to demonstrate strengths in visual spatial processing compared to individuals with SLD-R (31.8% versus 23.3%). The authors urge caution, however, in interpreting these results, as it is perplexing how individuals with academic weaknesses in two areas (i.e. reading and writing) would be more likely to exhibit processing strengths than individuals with challenges in only one academic area (i.e. reading).

In the absence of a sufficient knowledge base regarding SD specifically, distinct impairments may also be hypothesized through research studying cognitive abilities contributing to writing achievement. This body of literature suggests that comprehension-knowledge, auditory processing, processing speed, and long-term storage and retrieval are most highly implicated in predicting writing achievement across age groups (Flanagan, Ortiz, & Alfonso, 2013; Floyd, McGrew, & Evans, 2008). A similar study by Cormier, Bulut, McGrew, and Frison (2016) found variance in writing ability was mostly accounted for by fluid intelligence, processing speed, and auditory processing, specifically amongst younger children (however performance on these tasks varied considerably by age). As such, it can be inferred that children who experience significant writing challenges would exhibit poorer performance in tasks requiring the aforementioned cognitive attributes.

Mixed Learning Disabilities

It is important to note that academic deficits, such as difficulties reading, writing/spelling, or arithmetic, often co-occur (Willcutt, et al., 2013). Although beyond the scope of this study, in relation to isolated disorders, children with mixed SLD (most commonly RD plus MD) typically present with the most pronounced cognitive deficits and intellectual profiles (Toffalini, Giofrè, & Cornoldi, 2017; Willcutt, et al., 2013). These findings suggest that cognitive deficits associated with learning disorders in isolation may be compounded in children with mixed SLD (Landerl, Fussenegger, Moll, & Willburger, 2009): However, evidence for such an additive effect is inconclusive at this time (Andersson, 2010; De Weerd, Desoete, & Roeyers, 2012; Kearns, 2010).

Comorbidity

It is generally known that children with LD are at high-risk for co-occurring internalizing and externalizing disorders; as such, understanding neuropsychological comorbidities is also necessary when conceptualizing needs for this population of children and youth. Evidence from research in this area is not specific to a Canadian context but can provide direction as to the types and frequency of challenges that co-occur for children with SLD within a Canadian context.

Externalizing Disorders

One of the most common co-morbid diagnoses are between LD – across subtypes – and Attention-Deficit/Hyperactivity Disorder (ADHD). Epidemiological research indicates that LD and ADHD (specifically inattentive type ADHD: Carroll, Maughan, Goodman, & Meltzer, 2005) occur more frequently within the general population than would be expected by chance: with rates ranging from 0.2% (United Kingdom: Carroll,

Maughan, Goodman, & Meltzer, 2005) to 3.7% (United States: Pastor & Reuben, 2008). Within clinical samples, overlap between LD and ADHD are quite higher, ranging from 31% to 45% (Dupaul, Gormley, & Laracy, 2013). Variations in prevalence rates are partially accounted for by differences in definitions for SLD. For instance, comorbidity rates differ across studies that define LD by general academic underachievement versus weaknesses in specific academic domains (25%-40% for RD, to 11-30% for MD, and 11-40% for WD: Sadek, 2018).

There is limited evidence also to suggest LD, and RD in particular, is associated with disruptive, impulsive, and conduct-related disorders, such as : Oppositional Defiant Disorder and Conduct Disorder (CD) (Hendren, Haft, Black, White, & Hoefft, 2018). Co-occurrence is expressed (mostly) as aggressive and delinquent behaviours (Dahle, Knivsberg, & Andreassen, 2011).

Currently, there is no clear consensus regarding the nature of this relationship: that is, whether disruptive behaviours lead to, or result from, academic difficulties. Some researchers have suggested that poor school performance – brought about by cognitive processing deficits - contributes to behavioural difficulties (e.g. aggression, withdrawal) through poor self-esteem and frustration with one's academic performance (Pagani, Tremblay, Vitaro, Boulerice, & McDuff, 2001). Other researchers have proposed that behavioural difficulties result from impaired problem-solving and goal-directed behaviour (i.e. executive functioning deficits) which disrupts classroom learning, thus hindering academic performance (Poon & Ho, 2014). Further complicating this issue, children with RD often experience behavioural issues across academic and non-academic contexts, resulting in a hypothesis that the existence of one challenge does not *necessarily*

cause the other. Although beyond the capabilities of this research, establishing directionality between academic underachievement and behavioural difficulties would inform decisions regarding support provisions during treatment planning (i.e. where the child is most in need of support).

Internalizing Disorders

Likewise, children affected by learning challenges are at higher risk of co-occurring internalizing problems compared to the general populous. Literature in this area suggests that this association most often applies to children and adolescents with RD and/or SD. For example, a review by Mugnaini, Lassi, La Malfa and Albertini (2009) of research covering 2000 – 2008 demonstrates a (relatively) high-incidence (20%-25%) of internalizing disorders/symptomatology, including depression, anxiety, and social withdrawal, amongst children with RD. Depression and anxiety often manifest as generally dysmorphic mood, negative view of self, loneliness, stress, and felt helplessness or powerlessness (Mugnaini, Lassi, La Malfa, & Albertini, 2009; Maag & Reid, 2006).

As with externalizing disorders/symptomatology, researchers have yet to reach a consensus regarding the nature of the relationship between academic underachievement and internalizing difficulties. Some contend that academic underachievement brings about internalizing symptomatology by lowering academic self-concept over time (Howard & Tyron, 2002). Others have proposed that anxiety detracts from learning in academic settings by interfering with cognitive processes required for effective reading, writing, and mathematic performance (Bryan, Burstein, & Ergul, 2004).

As suggested by (Maag & Reid, 2006), internalizing symptoms among children with learning challenges are often sub-clinical. However, the bi-directional nature of

these concurring conditions suggests that internalizing (and possibly externalizing) symptomatology and academic underperformance exacerbate one another over time in the absence of intervention opportunities (Mugnaini, Lassi, La Malfa, & Albertini, 2009). As such, co-occurring behavioural and socio-emotional difficulties are relevant, without exception, when conceptualizing the needs of children with learning challenges.

Social Participation and Quality-of-Life

Quality-of-life (QOL) is characterized by healthy functioning across academic, behavioural, social and emotional domains. Evidence suggests that emotional, social, and behavioural domains are more indicative of well-being amongst children with learning challenges than mere academic performance (Rotsika, Coccossis, Vlassopoulos, Papaeleftheriou, & Sakellariou, 2011). Although in its infancy, a definite pattern has emerged within this literature: bolstering claims that children with learning challenges and their families experience poorer QOL compared to families of typically developing children (Sakiz, Sart, Börkan, Korkmaz, & Babür, 2015). For example, Ginieri-Coccossis, et al. (2012) found that children with LD report poorer emotional well-being, lower self-esteem, and less satisfaction with social relationships compared to a typically developing control group.

Regarding sociability, a recent study by Bauminger-Zviely, et al. (2019) found deficits in social-information processing amongst children with LD – mainly encoding, response searching, and decision making – is mediated by poor language capacities (e.g. storing and chunking informational cues). These findings suggest challenges in social functioning will more likely occur amongst children who also present with language processing deficits. The association appears to be sustained through factors like:

difficulties with communicative competence, social competence, accurate self-concept, school performance, and poor self-regulation (Burstein, Bryan, & Ergul, 2004; Elksnin & Elksnin, 2004; Greenham, 1999; Bryan, Burstein, & Ergul, 2004). These results suggest that children with learning challenges are generally more likely to experience interpersonal problems: Arguing with friends, difficulty creating or sustaining friendships, experience with bullying, attachment to parents and social anxiety (Wiener & Schneider, 2002; Nabuzoka, 2003).

Unsurprisingly, managing their child's academic, behavioural, and social-emotional needs contributes to strain and stress on an already full parent workload. Compared to parents of typically developing children, parents of children with learning challenges are more likely to experience anxiety, depression, and feelings of guilt, denial, and frustration (Silverstein, 2015). Anxiety is often attributed to parent's concerns relating to their child's school performance, acting out behaviours, and future development (Karande, Kumbhare, Kulkarni, & Shah, 2009). Other such concerns might include parent's (over)involvement in remedial education services, difficulties working with uncooperative and unconcerned school personnel and difficulties managing their child's reactions to special supports/services (Waggoner & Wilgosh, 1990). Feelings of guilt are frequently attributed to parent's poor self-image; often described through self-perceptions that they are "bad parents", especially under circumstances where they are unable (for whatever reason) to manage their child's needs (Fernández-Alcántara, et al., 2017).

According to Bronfenbrenner's ecological-systems theory, parent's QOL may have implications for the quality of care provided to their child (Bronfenbrenner, 1986). Consequently, effective interventions for children with learning challenges may

necessitate evaluation and support of the needs of parents in addition to the child's. However, what is known in this area suggests that the needs of parents with children impacted by learning challenges are rarely taken into consideration when providing supports and services. In an exploration of Chinese couples' perceived educational and health-related needs, Chien and Lee (2013) found that parents frequently eluded to inadequate support for their own physical and psychosocial health concerns. A similar study by Silverstein (2015) suggests that parents of children with learning challenges often experience insufficient help inside and outside of school, frustration with school and community professionals, and the perception of not being taken seriously. Arguably, addressing these concerns may extend beyond simply meeting the child's unique needs, such that efforts are made also to ease parent's emotional reactions (for example, through personal therapy or support groups; Fernández-Alcántara et al., 2017). The apparent paucity of support for parent's warrants ongoing consideration to how children's learning challenges interfere with family functioning and well-being: further, how educators, professionals, and school system might help meet these concerns.

Self-Determination

Rights-based approaches are founded upon the belief that persons most affected have a right to participate in decisions that impact them (Sherlaw & Hudebine, 2015): Alternatively speaking, enacting human-rights and entitlements requires users' active engagement. Engagement may be defined as a multi-dimensional construct consisting of internal (i.e. thoughts, emotions) and external/observable (i.e. behavioural) dimensions indicative of one's relationship to and interactions with a given social organization (Sharkey, You, & Schnoebelen, 2008). Importantly, process models of engagement often

presuppose the presence of psychological factors (e.g. motivation) that galvanize activity. It is the authors perspective that psychological factors associated with Wehmeyer and Schwartz's (1997) model of self-determination - autonomy, self-regulation, psychological empowerment, and self-realization – is most suitable to supporting the engagement of children and youth within a human-rights context. As such, self-determination is defined here as acting in a self-directed manner in pursuit of personally relevant goals (or optimal challenges) well suited to the actor's competencies (Wehmeyer & Schwartz, 1997) . Bearing in mind this model incorporates a framework for intervention – involving instructional planning and activities targeting foundational self-determination skills (e.g. choice making, decision making, self-management, etc.) (Shogren & Turnbull, 2006) – Wehmeyer and Schwartz's self-determination framework appears most relevant to the current study. Efforts to promote self-determination amongst school-aged children are supported by an abundance of evidence linking satisfaction of basic psychological needs to greater individual growth and development (Shogren & Shaw, 2016). Autonomy-supportive teaching, for example, has been linked to greater intrinsic/internalized motivation (Pelletier, Ségion-Lévesque, & Legault, 2002) and improved academic outcomes (Su & Reeve, 2011).

Beyond school, there is a strong correspondence between ratings on self-determination and advocacy skills and early adult outcomes indicative of quality-of-life – including independent living, access to services, health status, post-secondary education, financial supports and sustained employment (Shogren & Shaw, 2016). This seems particularly relevant for children with learning challenges, as it is often more difficult for such children to elicit early-stage self-determination skills relative to typically developing

children (Clark & McDonnell, 2008). Furthermore, research suggests that children presenting with functional impairments experience the (general) classroom environment as more controlling relative to their typically developing peers: what's more, their experiences exacerbate feelings of incompetence, and poorer student-teacher relationships (Rogers & Rosemary, 2018). This association is bolstered by literature demonstrating that intervention efforts designed to promote self-determination and self-advocacy skills amongst school-age children with learning challenges improves post-school (adult) outcomes (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015). Such findings make clear the need to evaluate current efforts at promoting self-determination amongst school-aged children with learning challenges.

The Present Research

Exploratory analysis was used with the intentions of:

- 1) Understanding the range of needs (academic, social-emotional, behavioural, and self-determination) associated with children's learning challenges and the needs of their parents and caregivers.
- 2) Identifying community, professional, and school-based services that parents have accessed in response to their child's needs.
- 3) Exploring the extent to which these supports are perceived as meeting the needs of their child.

The research study was divided into two-parts. First, we used standardized assessment measures to elucidate academic, behavioural, socio-emotional, familial and self-determination based needs experienced by children impacted by learning challenges and their families. Second, we examined parent's perceptions of support provided for

children with learning challenges. Study materials and procedures were approved by the Western University Non-Medical Research Ethics Board (WREB) (Appendix A).

Methods

Study Methodology

A triangulation study approach was used, in which qualitative data was used to inform quantitative findings (Williamson, 2005). Quantitative data sources showed how learning challenges impact children and their families across various domains. Qualitative findings, retrieved through semi-structured interview, will illustrate parent's caregiving experiences as they relate to providing adequate support either directly (i.e. parenting strategies) or indirectly (i.e. through community, professional, or school-based services) to address relevant needs.

Sample

Study participants were recruited using a combination of purposive ($n = 8$) and convenient ($n = 2$) sampling procedures directed at parents within London, Ontario and its surrounding counties (Elgin, Middlesex, Oxford) who suspect that a learning challenge is affecting their child's adaptive functioning. Purposive sampling will ensure a diversity of important details suitable to answering the research question (Munhall & Chenail, 2008). Regarding the current study, recruiting families from multiple service types will allow for a more comprehensive evaluation of services intended to support children's learning challenges. Convenient sampling was used to compensate for low-response rates caused by a significant drop-off in on-site service use during the current COVID-19 pandemic. Two study participants were recruited using convenience sampling procedures

whereby parents were approached who had recently been connected to services at the Child and Youth Development Clinic (CYDC) to support their child or family.

Recruitment material was distributed via email (Appendix B) to a variety of referral sources, including: psychologists operating within private practices, local agencies supporting children with LD (Learning Disability Association of London; Vanier Children's Service; Welkin Child and Youth Wellness, The Mary J. Wright Research and Education Centre at Merrymount). Recruitment material were also distributed to families on waitlist for services delivered through the Child and Youth Development Clinic (CYDC) (Appendix C) who had consented to receive clinical and research participation opportunities. Recruitment emails contained PDF versions of WREB recruitment material (Appendix D).

Inclusion criteria were: (a) Parents suspect that a learning challenge is negatively impacting their child's academic performance, behaviour, and socio-emotional development. (b) The child is enrolled in elementary school (Kindergarten – Grade 8). (c) The child has not received a psychological assessment for a formal diagnosis of LD. Families were to be excluded if their child had been diagnosed or was eligible to be diagnosed with a neurodevelopmental disorder (e.g. Intellectual Disability, Autism Spectrum Disorder, Down Syndrome), excluding Attention- Deficit/Hyperactivity Disorder (ADHD). This exception reflects research that suggests significant overlap in symptomology, and therefore high rates of comorbidity, between LD and ADHD (Sahoo et al., 2015).). If the child had received a diagnosis of ADHD, the parent must have indicated that a learning challenge was an additional unique contribution to their child's current challenges.

Data Collection

The recruitment period ran between February 2020 and March 2020. Families were assessed for study inclusion using a structured telephone interview protocol (Appendix E). During screening, the researcher provided a detailed description of the purpose of the study, study procedures, and contact information for the principal investigator for parents seeking additional information. Following, the researcher confirmed eligibility for study inclusion. Those invited to participate were scheduled for a follow-up appointment to occur either in-person at the CYDC or via telephone.

After administering a Letter of Information (Appendix F) and obtaining written consent, the researcher facilitated a semi-structured interview (Appendix G) to explore parent's caregiving experiences. Interviewers conducted several meetings before initiating data collection whereby they generated a standardized protocol for conducting semi-structured interviews, therefore reducing potential inconsistencies. Where appropriate, the principle investigator and student investigator exchanged feedback regarding noticeable differences in interviewing practices. Following semi-structured interviews, parents were provided a series of assessment measures intended to assess parent-reported academic, behavioural, socio-emotional and familial concerns. At the same time, parents filled in a brief unstandardized form requesting demographic information relating to themselves and their child (Appendix H).

Two families scheduled after the Ontario government initiated social-distancing protocols were provided study instruments electronically and interviewed via telephone. Semi-structured interviews were audio recorded and transcribed using the TRINT automated transcription software. Researchers reviewed the resulting transcripts and

performed minor edits to ensure clarity. As recognition for their participation in the study, parents received a summary recommendation report (Appendix I) outlining patterns in their child's strengths and weaknesses indicated by assessment measures, along with recommendations for potential strategies, supports, and services.

Measures

Colorado Learning Difficulties Questionnaire (CLDQ)

The CLDQ (Willcutt, et al., 2011: Appendix J) is a 20-item, parent-report questionnaire designed to measure children's functioning in domains that are commonly observed in LD, such as reading, writing, social cognition, memory, and spatial awareness. Parents responded to each item using a 5-point Likert scale (1 being "Never/Not At All" and 5 being "Always/A Great Deal"). The CLDQ demonstrates moderate-high inter-rater reliability, test-retest reliability, and validity (Willcutt, et al., 2011)

Quality of Life for Children and Adolescents with Learning Problems (LD/QOL15)

The LD/QOL15 (Waber, Boiselle, Forbes, Girard, & Sideridis, 2018: Appendix K) is 15-item parent-report questionnaire intended to assess the quality of functioning of children and adolescents with learning challenges. This measure provides several indices of academic and psychosocial functioning, including: academic performance, school understanding, and school/family functioning. Parents responded to each statement using a 4-point Likert scale (0 being "Never/Strongly Agree and 3 being "Most of the time/Strongly Disagree"). Waber and colleagues (2018) have demonstrated that the LD/QOL15 instrument has high reliability, and good criterion and convergent validity.

Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997: Appendix L) is a 25-item parent-report questionnaire designed to assess children's psychosocial behaviours. The questionnaire is divided into five subscales: Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Problems, and Pro-social Behaviour. Parents were asked to rate their child's behaviours using a 3-point Likert scale (0 being "Not True" and 2 being "Certainly True"). Subscales are categorized as positive (Pro-social Behaviour) and negative (Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Problems). Negative subscales were summed to provide a total Difficulty score. The reliability and validity of the SDQ has been demonstrated in multiple studies (Kersten, et al., 2015).

Semi-structured interview

Interview questions were based on the interview guide used by Chien and Lee (2013) (Appendix G). This protocol was developed to explore caregiving needs for families of children with a SLD. These interview questions were reviewed by an expert panel that included representation from health professionals (e.g., child psych etc.) For this study, several questions were added to investigate parent's perceptions of engagement and self-determination for their child and the quality of accessed supports. The interviews took approximately 45 minutes to complete, and was audio recorded.

Data Analysis

This study utilizes a convergent parallel mixed-methods design, in which quantitative and qualitative data are analyzed independently, and converge at the point of data interpretation (Schoonenboom & Johnson, 2017). To address the first research question, we present prevalence rates across several levels of severity (i.e. normative,

borderline/at-risk and clinical) for academic, behavioural, socio-emotional and familial needs within the current sample. Prevalence rates were determined by contrasting parent's responses to pre-established cut-offs across CLDQ, LD-QOL/15, and SDQ subscale measures.

The second and third research questions were addressed through applying qualitative content analysis to interview transcripts. The goal of the qualitative content analysis was to identify themes that reflect parent's experiences as caregivers, as well as perceptions of engagement, self-determined behaviour, and quality of accessed supports. The analysis process followed guidelines described by Elo and Kyngäs (2008). Given the lack of available literature on this topic, the analysis will use an inductive approach, meaning categories and themes will be adapted from raw data. In accordance with Elo and Kyngäs (2008), the analysis was divided into three phases: preparation, organization, and reporting.

During preparation, the research team collectively agreed upon a suitable unit of analysis. For consistency, meaning units were defined similarly to Chien and Lee (2013). As such, meaning units were derived from words, phrases, and sentences. Following, the student researcher reviewed each transcript to gain familiarity with interview data. Notably, the student researcher had established some familiarity already when interviewing study participants and editing the resulting transcripts. Preparation continued with open coding, whereby the student researcher re-read each transcript and identified meaning units that appeared relevant to the research focus. Meaning units were paired with brief comments that summarized the student researcher's initial impression of

the text. The preparation phase concluded with meaning units being assigned succinct codes that denote their significance.

During the organization phase, meaning units were arranged into categories based on relatedness to a common theme. Organization was assisted by uploading transcripts to Dedoose (V8.3.17); a cloud-based mixed-method analysis software. This software allowed researchers to collect codes across transcripts into a single electronic spreadsheet (or database). Once uploaded, the researcher initiated an iterative process of grouping meaning units into subcategories based on commonalities between the assigned codes. Likewise, subcategories were grouped together to form categories, and categories grouped together to form themes. Following a full review, the student researcher re-evaluated the resulting categories and themes to assess their appropriateness to the research focus (Erlingsson & Brysiewicz, 2017). Final themes and categories were transferred to a codebook and provided unique descriptions (Appendix M). To promote trustworthiness, the codebook was reviewed by the principal investigator (Gilstrap, 2004). Following their review, the principal investigator discussed their opinions on the suitability of categories and themes with the student researcher. Afterwards, both parties deliberated any recommendations provided by the principle investigator, and revised categories and themes in accordance with their final verdict.

Our analysis resulted in three overarching themes, each containing several categories and/or subcategories of codes. Dedoose was used to count the number of instances with which each code appeared across transcripts. Findings from the qualitative content analysis were restricted to codes that emerged most frequently (i.e. appearing in

at least 4 separate transcripts). Codes are presented alongside example excerpts and discussed in relation to the research focus.

Results

Interview Participants

The study sample consists of 10 parents, all of whom identified as female. Ages of participants ranged from 28 to 53 years of age, with an average age of 43.4 years ($SD = 8.16$). Eight study participants were employed (7 full-time; 2 self-employed), and all study participants had a secondary-school education or higher as their highest education received (2 secondary school; 5 undergraduate degrees; 1 graduate degree; 2 college diplomas). Eight participants indicated being in a relationship (6 married and 2 common-law), 7 expressed having religious beliefs (5 Christian; 1 Catholic; and 1 Anglican), and 9 identified as Caucasian. Children under investigation were mostly male ($n = 8$), with ages ranging from 6 to 14 years of age, with an average age of 9.4 years ($SD = 2.15$).

One study participant's child (14 years of age) fell just outside of the age range originally listed in the study inclusion criteria. After review, a decision was made to include this participant in the final sample, as the child's learning challenges were longstanding and had been recognized during their elementary school years. Their data was included due to similarities between their experiences and those of other families included in the final sample.

Data Analysis

Cut-off points for the SDQ and LDQOL/15 were developed by the instrument authors (Waber, Boiselle, Forbed, Girard, & Sideridis, 2018; Goodman, 1997), and were utilised to determine the type and severity of challenges ascribed by parents of children

within the current sample . As the CLDQ has only recently been validated for use as a screener for LD, cut-off points for this measure were only available for reading and math achievement (Patrick et al., 2013). Cut-off points for study instruments are presented in Table 2. Table 3 shows means, standard deviations and prevalence rates for normal, at-risk, and clinical cases using the above-mentioned assessment standards.

Table 1*Demographic Characteristics of Parents and Children**(N = 10)*

| Characteristics | Frequency (<i>n</i>) |
|-----------------------------|------------------------|
| <i>Parents</i> | |
| Age (yr) (M; SD) | (43.4; 8.16) |
| 25-34 | 2 |
| 35-44 | 2 |
| 45-55 | 6 |
| Sex | |
| Female | 10 |
| Marital Status | |
| Common-Law | 2 |
| Divorced | 2 |
| Married | 6 |
| Employment Status | |
| Employed (Full-Time) | 7 |
| Small Business Owner | 1 |
| Unemployed | 2 |
| Race/Ethnicity | |
| Caucasian | 9 |
| Tri-racial African American | 1 |
| Faith | |
| Anglican | 1 |
| Catholic | 1 |
| Christian | 5 |
| None | 3 |
| Highest Education | |
| College | 2 |
| Secondary School | 2 |
| Graduate Studies | 1 |
| Undergraduate Studies | 5 |
| <i>Child</i> | |
| Age (yr) (M; SD) | (9.4; 2.15) |
| 6 – 8 | 5 |
| 9 – 11 | 4 |
| > 11 | 1 |
| Sex | |
| Female | 2 |
| Male | 8 |

Table 2*Cut-Off Points Across Levels of Severity for CLDQ, SDQ and SDQ Subscales*

| | Normal range | At-risk range | Clinical range |
|--------------------------------|--------------|---------------|----------------|
| CLDQ | | | |
| Reading | < 2.67 | - | > 2.67 |
| Math | < 2.60 | - | > 2.60 |
| SDQ | | | |
| Emotional symptoms scale | 0-3 | 4 | 5-10 |
| Conduct problems scale | 0-3 | 4 | 5-10 |
| Hyperactivity scale | 0-5 | 6 | 7-10 |
| Peer problems scale | 0-3 | 4 | 5-10 |
| Pro-social behaviour scale | 6-10 | 5 | 0-4 |
| Difficulty | 0-12 | 13-15 | 16-40 |
| LDQOL/15 | | | |
| Academic performance | 0-5 | 6-8 | > 9 |
| School understanding | 0-4 | 5-6 | > 7 |
| Child and family psychological | 0-5 | 6-9 | > 10 |

Note: CLDQ = Colorado Learning Difficulties Questionnaire; SDQ = Strengths and Difficulties Questionnaire; LDQOL/15 = Quality of Life in Children and Adolescents with Learning Problems Scale

Table 3*Means, Standard Deviations (SD) and Prevalence Rates (N = 10)*

| | Mean | SD | Prevalence (<i>n</i>) | | |
|--------------------------------|-------|------|-------------------------|---------------|----------------|
| | | | Normal range | At-risk range | Clinical range |
| CLDQ | | | | | |
| Reading | 2.97 | .90 | 5 | - | 5 |
| Math | 3.10 | 1.14 | 4 | - | 6 |
| SDQ | | | | | |
| Emotional symptoms scale | 3.30 | 2.24 | 4 | 4 | 2 |
| Conduct problems scale | 3.90 | 1.87 | 5 | 2 | 3 |
| Hyperactivity scale | 6.90 | 1.92 | 2 | 3 | 5 |
| Peer problems scale | 3.80 | 1.47 | 4 | 4 | 2 |
| Pro-social behaviour scale | 8.20 | 1.54 | 10 | 0 | 0 |
| Difficulty | 17.90 | 4.44 | 0 | 3 | 7 |
| LDQOL/15 | | | | | |
| Academic performance | 7.40 | 1.80 | 1 | 5 | 4 |
| School understanding | 7.40 | 1.69 | 1 | 1 | 8 |
| Child and family psychological | 7.80 | 1.99 | 2 | 6 | 2 |

Note: CLDQ = Colorado Learning Difficulties Questionnaire; SDQ = Strengths and Difficulties Questionnaire; LDQOL/15 = Quality of Life in Children and Adolescents with Learning Problems Scale

Qualitative Content Analysis

The following figures and illustrations show codes, categories and themes selected for further analysis and interpretation. Each figure includes prevalence rates denoting the frequency with which codes appear across transcripts.

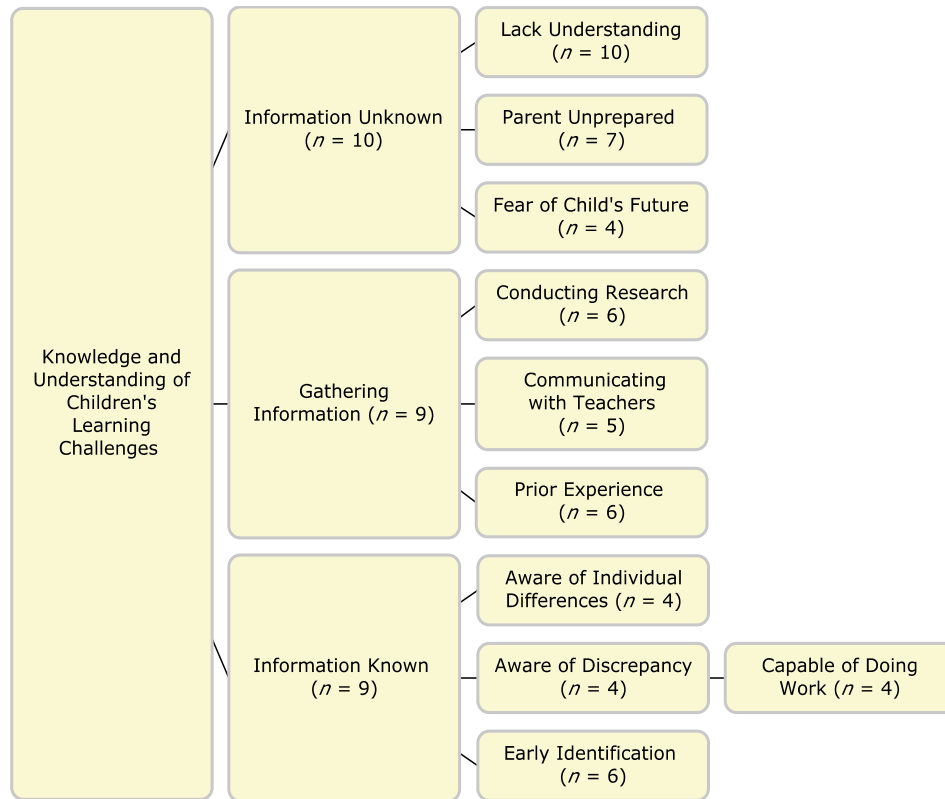


Figure 1. Parent's Knowledge and Understanding of their Child's Learning Challenges

Parent's Knowledge and Understanding of their Child's Learning Challenges

While discussing their role as care providers, parents expressed a range of information needs related to caregiving and their role as a parent.

Lack Understanding. All parents expressed uncertainty regarding the origin and cause of their child's learning challenges, although the manner in which this uncertainty was expressed varied substantially. Several parents questioned whether the severity of their child's challenges was indicative of a LD:

...it just seems to be such a small thing because he does do fairly well. I guess there's a lot of questioning like, you know, are we really truly seeing something or are we not? Is it something to be super concerned about? (ID 009)

Limited knowledge regarding their child's learning challenges at times resulted in difficulties delineating normative from atypical behaviours. As one parent stated, "So, again, is it the age? Is it...you know, I'm not quite sure." (ID 005). On the contrary, some parents felt confident that their child was affected by a LD, but unsure to what extent their child's challenges could be attributed to a LD versus other potential complications. For example, one parent stated, "At this point, it's not a surprise – we are pretty sure she has a learning disability – we just don't know to what extent and what other problems might be there." (ID 007)

Parent Unprepared. Importantly, parents perceived the paucity of information available to them regarding the nature of their child's challenges as a hindrance in their efforts to provide adequate support:

You know, one of the reasons I'm here is because I'm trying to figure out more about him and how I can help him. And that's been a constant for me with my son. I've been trying to, you know, looking at different angles, reading, trying to figure out, you know, how to help him." (ID 006)

Their limited understanding often elicited feelings of being ineffective care-providers. To illustrate, one parent matter-of-factly stated, "We're screwing things up badly as parents." (ID 005). While elaborating similar concerns, one parent voiced trepidation that their

inability to provide effective care would interfere with their child's emotional development. This parent stated: "I worry that I'm doing an injustice, that he may grow up with mental health challenges, that maybe if I had parented differently, I could prevent." (ID 004)

Fear of Child's Future. While reflecting on their current circumstances, some parents expressed having concerns about their child's future. A number of parents expressed doubt regarding their child's ability to progress and successfully meet the later demands of adult life:

So how much is that going to play a role throughout his whole life until he can find kind of a career path or education path where he flourishes with something that's probably more hands on or geared towards his interests versus the kind of academic demands at his age that, you know, don't kind of fit the way he functions. (ID 010)

You know, you need to see a little bit of initiative, too, I guess. And some responsibility perhaps on his part to see, you know, to prepare. Ultimately, you know, just to make sure that he's OK to be on his own later in life, just moving, moving along right. (ID 006)

Parents who elaborated emphasized how their concerns and worries appeared justified by the hardships they experienced thus far in addressing their child's needs.

Prior Experience. What limited knowledge parents had accumulated regarding the nature of their child's challenges (including information related to caregiving) often developed independently of external sources. Many parents referenced prior experiences

and/or expertise as a dominant source of information while attempting to understand their child's difficulties. Several parents utilized their own and/or their partner's history of learning challenges to gain insight into their child's experiences:

My husband struggled in school a lot with reading, so we ended up having a lot of talks and conversations along the way about what it "looked like" and how it was experienced from his end. (ID 007)

... my brother was dyslexic, so I grew up with it with him. It's easier for me to recognize because I have the background to see what's happening. (ID 001)

Two parents mentioned turning to former educational experiences to support their efforts, particularly while managing their child's mental well-being. These parents recognized that performing well academically required maintaining their child's total health, including their emotional health.

Conducting Research. In the absence of prior experiences, expertise or external supports, many parents relied upon conducting their own research. Research queries varied with regards to their intended purpose. As expected, most parents sought out prior literature that would enhance their understanding of the nature of their child's learning challenges. In light of parent's self-reported ill-preparedness, it is unsurprising to note that parenting strategies were also identified as a primary research focus. As this parent suggested, "There's a lot of worrying and a lot of thought and a lot of reading that goes into trying to appropriately parent." (ID 004). Less expectedly, having recognized the quality of support their child was receiving through school, parent's also identified

teaching methods for educators as a supplementary research focus: “So you didn't go to school to learn this stuff, but you have to research it so that you can help them to help your kids.” (ID 001)

Communicating with Teacher. Most parents acknowledged the importance of gathering information from multiple sources, and noted frequent communication with their child’s teachers. The content of these discussions focused around gathering information about their child’s behaviour and gaining additional insight into likely underlying cognitive weaknesses and/or potentially useful intervention techniques. Unfortunately, however, parents perceived that they were often responsible for initiating contact with educators:

Why is that the parent’s responsibility then to find out what’s going on and call the school? Why is the school not having conversations with us saying that? This is what I’ve noticed? Because in my experience, every issue I’ve had, I’ve had to call in, not someone calling me. (ID 001)

Aware of Discrepancy. Interview data showed that parents had (some) knowledge regarding fundamental realities of learning challenges. To illustrate, several parents stated their awareness of their child’s capabilities exceeded what was perhaps suggested by their academic performance:

I really do think that there’s something, and I think he can see it too to a certain degree from showing his capabilities [like he’s pretty. You know], I think he’s very bright. I think he’s very capable. (ID 006)

As in the above example, most parents demonstrated knowledge of such discrepancies by describing instances wherein their child was capable of completing tasks assigned to them in certain circumstances or context. As one parent stated, “If he is interested and exciting to do it – no problem, it gets done.” (ID 002)

Aware of Individual Differences. These same parents also recognized the diversity that exists among children experiencing learning challenges, as evidenced by comments alluding to their child’s responsiveness to various treatment modalities: “...each person has their own thing that they respond to. And knowing that helps a lot...” (ID 001). Multiple parents expressed knowledge of their child’s idiosyncrasies (albeit indirectly) by commenting to patterns of strengths and weaknesses. As one parent commented, “...why is a ‘C+’ the best that she can do in some areas and why are other areas higher like high B?” (ID 001). Consistent with the PSW approach (Christo & Ponzuric, 2017), one parent, whose child (reportedly) experienced severe behavioural difficulties, identified reading as a notable strength: “Like all the way up to Grade 2, he hid how he was reading at a grade 4 level.” (ID 005).

Early Identification. Notwithstanding an official diagnosis, the majority of parents had recognized potential learning challenges well before most institutions including school and community services would support a formal evaluation. Prior to enrolling in elementary school, such difficulties were often recognized through observable behaviours by parents at home. Conversely, one parent noted irregularities in their child’s arithmetic skills prior to Kindergarten. Even so, most parents hadn’t explicitly acknowledged their child’s (potential) learning challenges until grade one or two:

My husband has dyslexia – or at least I’m pretty sure he has it – he hasn’t been formally assessed. However, he basically shares that my daughter’s journey right now is what school has been like for him. He hated school and couldn’t learn to read – I think it was Grade 6 or 7 that it finally began to “come together” for him. So when she started school and had a hard time beginning to remember the letters and their sounds – we were like “oh no”. (ID 007)

I learned very early, probably grade two, [I knew] that there was something with his reading. (ID 003)

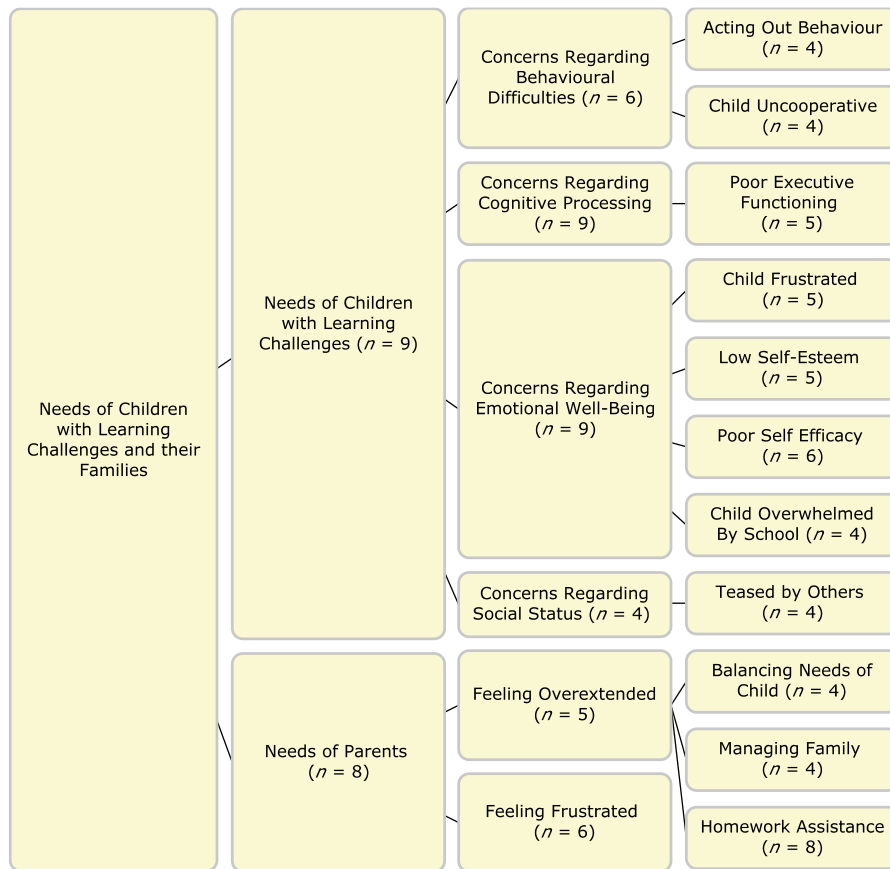


Figure 2. Needs of Children with Learning Challenges and their Families

Needs of Children and Families Impacted by Learning Challenges

Two overarching themes emerged regarding needs associated with children's learning challenges: intrapersonal (i.e. concerning the child's experiences) and familial (i.e. concerning the parent's role in managing their child's learning challenges). Intrapersonal concerns for children affected by learning challenges focused on areas of emotional, behavioural, cognitive and social need.

Poor Self-Esteem. A prominent subtheme that emerged was parent's concerns regarding their child's self-esteem (i.e. feelings of self-worth). Comments alluding to self-worth most often referenced the child's academic underachievement. One parent explained: "...he already sees himself as a dumb kid in class. The kid who is not the same as the others." (ID 010). Select parents referenced poor self-esteem as resulting from the child's behavioural difficulties: "After he blows up, he can say some pretty difficult things to himself that it is hard to hear. Things like, he is a "bad kid" and "he should be out of the family." (ID 002)

Poor Self-Efficacy. Parents made similar remarks regarding their child's self-efficacy (i.e. belief in one's own capabilities). These comments focused around difficulties their child had experienced in overcoming challenges that affected them. As one parent recalled, "She said it's no good. I can't understand this. I'm never [going to] get it. And that's it." (ID 001).

Child Frustrated. Most parents mentioned their child experiencing frustration – typically as a consequence to poor school performance. Such frustration seemed to hinder the child's participation in activities that require managing their learning challenges:

There was one point about a month ago where she was so shut-down around school work. She literally wouldn't pick up a book to look at words – she was so resistant. (ID 007)

Child Overwhelmed by School. Several parents emphasized the extent to which their child's interactions with school systems contributed to their frustrations. However, parents varied regarding their perceptions of the likely source of these frustrations. Some parents called attention to their child feeling overworked. Others remarked that educators at the school were reluctant to accommodate their child's performance levels: "...when he's in the school room. They're teaching at the grade 5 level, which he's not able to do." (ID 003). Such methods render these children exhausted by day's end; further crippling their motivation and/or willingness to engage with homework assignments and/or recreational activities. Importantly, recreational activities were often identified by parent's as a significant contributor to their child's self-care.

Child Uncooperative. Many parents expressed concerns that their child behaved inappropriately, either refusing to follow direction or acting verbally or physically abusive towards others, such as the parent, the child's peers, or their siblings. Parent's accounts of their child's cooperativeness varied in the extent to which the child's behaviour affected family functioning. Minor instances often manifested as dismissal, in which the child responds to their parents requests by "forgetting or ignoring it." (ID 009). More burdensome to parents were cases when their child's inability (or refusal) to follow direction resulted in experiential avoidance: "When he was a little bit younger, I did avoid going to restaurants for a while because he was running around all the time and wouldn't listen." (ID 004). This parent explained afterwards that their actions were

intended to keep away from situations that might cause others to judge their apparent inability to regulate their child's behaviour. While discussing a recent experience of caregiving, the parent stated:

...I guess I worried how the gym would look upon us. They know us, too. So there's that judgment that's coming to me as a parent, not having my kids follow the rules that are laid out. (ID 004)

Multiple parents commented that their child behaved in a similar fashion towards educators at school or other people in a more general sense: "He's a very strong willed child. So that in and of itself is a challenge. Teachers find it challenging, and people find it challenging." (ID 005).

Contrary to these illustrative cases, in which the child's behaviour appeared consistent across situations, one parent described unaccommodating behaviour as context specific – such as a reaction to being denied something desirable:

...if he doesn't do the 15 minutes of French, then he doesn't get the next block. And then when that happens. It's, well you didn't give me what I wanted. I want to go home now. (ID 008)

Acting Out Behaviour. For some parents, their child's conduct issues had progressed beyond mere disobedience, to the point of behaving rowdy or aggressive (i.e. acting out). Moderate behavioural difficulties of this classification involved the child (literally) "acting out" their disagreement:

...sometimes he knows that he's supposed to be participating and so he'll be rolling around on the floor. Protesting basically is what he's doing. Saying, I don't want to do this, I don't want to play... (ID 004)

More severe cases involved the child behaving in a physically aggressive manner:

He used to completely shut down and just not say anything. They gave him a selective mutism diagnosis. Now, instead of shut downs, it's blow ups, hitting walls, throwing things, tormenting his siblings. (ID 008)

Two of these parents revealed having knowledge obtained through either direct observation or teacher-reports of their child threatening and/or attempting to injure a sibling/peer.

Teased by Others. Parent's social concerns mostly centred around their child's social status: specifically, how they were being treated by others. Although parents never directly shared their child's perceived social status, the range of behaviours they commented to – including verbal and physical bullying – suggested their children often occupy a lower-class relative to their peers. Without quoting comments their child had received, multiple parents referenced their child returning home “upset with certain things kids say” (ID 003). One parent shared their child had been tripped a lot during recess periods. (ID 001). This parent's concerns were exacerbated by knowledge of their child lacking assertiveness: “That's really tricky for her, standing up for herself on the playground.”(ID 001). Their child's passivity was particularly troubling in light of perceiving educators as condemning the child in question for *their* inappropriate behaviour during these interactions:

...when she talks to them about something happening, she feels that they're immediately coming at her, like, what could you have done to prevent what happened to you? (ID 001)

Another parent commented to a similar type of mistreatment emanating from within their child's friend group:

It was, it was strange for me because there was a lot of negativity there. His friend was saying a lot of mean things about my son. And my son was, you know, had some comebacks, but I really didn't see [sort of] a supportive friendship. (ID 006)

This parent's concerns, however, were moderated by their child openly acknowledging the potential for harm imbedded in their relationship, and that they (the child) managed the situation accordingly. Quoting their child, one parent stated, "We were playing around. But then he actually said something mean about my diabetes. So I said, for me, that was like the last straw. (ID 006)

Poor Executive Functioning. Although cited less frequently, some parents had identified cognitive-processing deficits they presume are contributing to their child's learning challenges. These parents generally attributed their child's weaknesses to executive functioning challenges, such as difficulties remaining focused and poor working memory. Such weaknesses were illustrated by comments referencing their child's difficulties following directions:

I might say [son], will you get me the pencil on the counter in the kitchen? And he'll go into a completely different room and say, I can't

find it. Where's the kitchen [son]? It takes them a while so that I find perplexing. (ID 004)

One parent specified their child's reading difficulties as uniquely associated with their ability to discern letter-sound sequencing for sight words. In the absence of more detailed information, multiple parents simply stated their child was experiencing challenges reading and/or writing. Interestingly, less than half of parents identified academic underperformance as their primary concern for caregiving.

Feeling Frustrated. A prominent finding, evidenced by most parents, concerned the challenges that parents experienced as a consequence to managing various aspects of their child's learning challenges. When asked about thoughts and emotions associated with their role as caregivers, most parents expressed feeling frustrated. Study findings suggested parent's frustrations most often result from problems directly supporting/guiding their child – usually as a consequence to behavioural difficulties (i.e. behaving uncooperatively or acting out publicly):

*When he acts out in public or doesn't follow directions, I'm frustrated.
(ID 004)*

I get mad at him, or I'll call him by that guy's name. It's like do your eye exercise, do you want to grow up like that. (ID 005)

One parent ascribed their frustrations to helplessness providing homework assistance. Recalling a recent experience, this parent stated, “The homework didn't get done, he was crying, my husband was super frustrated, and I was on the verge of tears...” (ID 002). Many parents viewed their frustrations as a reaction to criticism received by their child's

teacher – usually being that parents were neglecting their caregiving responsibilities. To illustrate, one parent recalled their child’s teacher making the following comment: “Saying to us we just need to do more when we're already doing that to me is really frustrating, because you don't know what I do...” (ID 001).

Feeling Overextended. Contrary to (some) teachers’ opinions, having accepted the onus of responsibility, many parents expressed feeling exhausted in their efforts to support their child. While discussing their child’s Individual Education Plan (IEP), one parent commented how educators were perceived to idly apply their child’s assigned accommodations with little-to-no interest in generating creative solutions. Elaborating, this parent stated “that’s all on the parents.” (ID 001).

Balancing Needs of Child. Difficulties with problem solving were often amplified under circumstances where parents were tasked with managing multiple-interacting challenges:

I realize that is not so easy. You know, the way they presented it was like us, you know, it's manageable. And, you know, they don't tell you about people who have diabetes and, you know, how well they're doing it and. It's not that easy. It's definitely not that easy.” (ID 006)

Homework Assistance. These unique caregiving responsibilities, specific to supporting children with learning challenges, are supplementary to conventional aspects of caregiving: most notably, homework assistance. Interview data showed that parents varied in the extent to which they provided their child homework assistance. One parent described their engagement being limited to answering questions put forward by their child about their homework assignments. On the contrary, a few parents mentioned

dedicating multiple hours most nights aiding their children with homework assignments. One parent described their involvement as necessary for their child to progress through homework assignments:

You have to be there with him to do each step and say, okay, we've done this, what do we need to do next? Sometimes he can't come up with the answer. You have to basically say this is the next step. How do we approach that? (ID 010)

Managing Family. Complicating matter further, parents endeavoring to support their child with learning challenges were simultaneously managing interactions between family members. While discussing their use of various parenting strategies, one parent stated, "...you're seeing them start to take effect, which are less so effective if her brother's acting up." (ID 001). Several parents noted how their partner and/or other children would exacerbate associated challenges: "I try not to let his father get involved because it just always gets out of hand and it's his father's fault." (ID 005). One parent mentioned having themselves contributed to their child's behavioural difficulties:

He gets frustrated, [and] has some meltdown. It might be later in the day [so] I'm exhausted, and then I have a meltdown, and I scream and yell, and we get in this yelling match; this vicious circle. (ID 010)

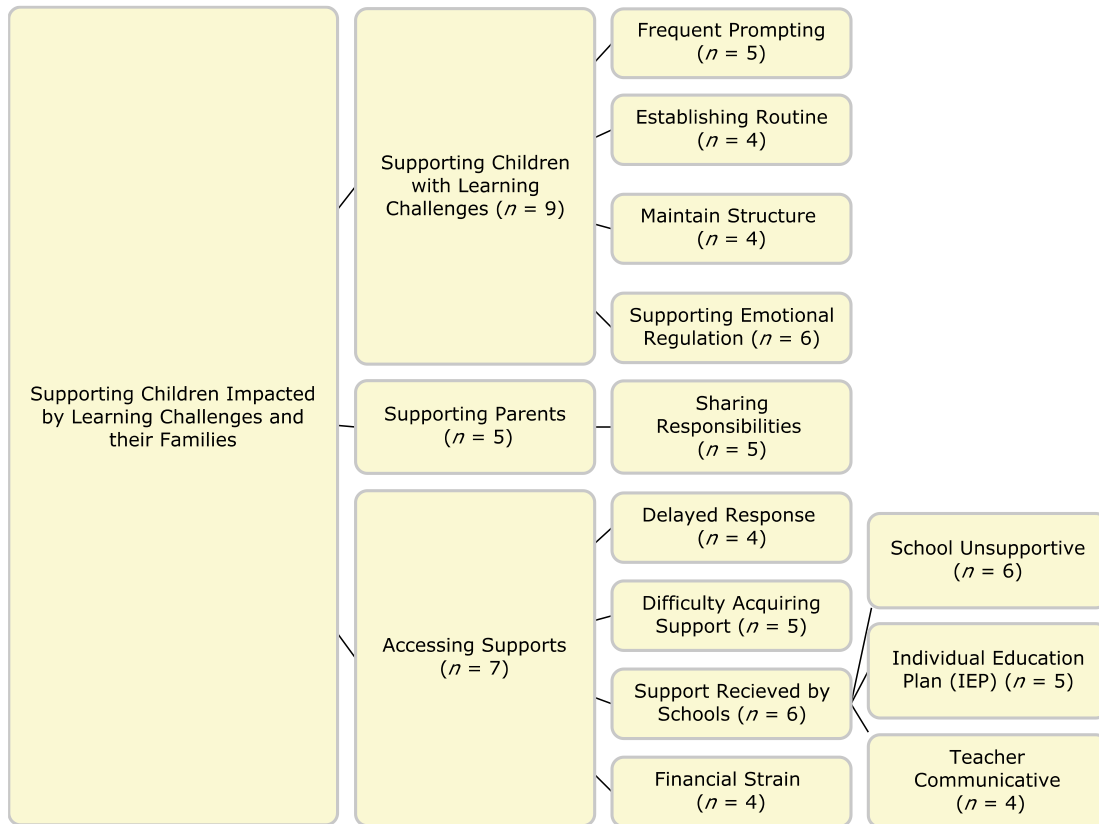


Figure 3. Supporting Children and Families Impacted by Learning Challenges

Supporting Children and Families Impacted by Learning Challenges

Acting as their primary support figure, parents are tasked with generating practical solutions for managing everyday care for their child. The range of techniques parents employed was often limited and focused on addressing needs associated with the child’s cognitive, behavioural, and emotional deficits.

Establishing Routine. Many parents discovered that their child’s challenges, cognitive, behavioural, or emotional, were often circumvented by establishing consistency in their day-to-day activities. Recalling a recent conversation with their child, one parent stated the following:

We're going to have the same routine so that when you come home from school, you know, this is where your coat goes. This is where your backpack goes. This is where the papers go to be put in this area to be signed and returned. Keep your books in your bag so they don't get lost. (ID 001)

Maintain Structure. Parents and school educators employed similar strategies, such as maintaining predictability through reinforcement-scheduling and planned breaks to assist in completing specific tasks:

...I usually set a timer and say, OK, we're going to do 20 minutes or 30 minutes, then you can have a 10 or 15 or 30 [minute] break. (ID 010)

...he's got a schedule of you know going you get 15 minutes in the wellness room, you do 15 minutes of French, you get 15 minutes to play. You do 10 minutes of this, you get ten minutes to play.

Frequent Prompting. In spite of their efforts to encourage productive habits, frequent prompting or re-direction was often necessary to moving through their child's daily routine. Interview data suggests that prompting was not restricted to specific tasks, but rather applied to most circumstances when their child is active.

Supporting Emotional Regulation. Their appeared to be greater diversity regarding parenting strategies targeting emotional regulation. Generally speaking, emotion regulation strategies varied with regards to the child's involvement. A few parents identified methods in which they themselves were responsible for regulating their child's emotions, such as spending one-on-one time, cuddling, and sharing positive

memories of their child. On the contrary, many parents reported using strategies that encouraged their child's participation. For example, one parent mentioned validating emotions and facilitating open discussions about their child's anxieties as the primary response to their child feeling dysregulated: "You know, just assisting him with you know talking through things, acknowledging something that might be making him feel anxious." (ID 009).

Sharing Responsibilities. Compelled with overwhelming responsibilities, care providers must also find ways to manage personal physical and emotional health concerns. Parents in married or common-law relationships often enlisted support from their partners to lessen their caregiving burdens. Alternatively for those who had separated house-hold responsibilities were divided between the parent and their child. Interestingly, only one parent indicated that they had acquired support in addressing their own behavioural/mental health concerns. This parent stated, "I have done therapy myself to try to do some anger management and figure out where my feelings are coming from." (ID 010).

Difficulty Acquiring Support. With regards to supports offered by schools and community services, many parents described the process of justifying their child's needs as onerous. They explained that gathering sufficient evidence "takes years" (ID 003), and requires that care providers "battle every step of the way." (ID 007). Gathering evidence is particularly burdensome for parents with children affected by behavioural difficulties. As one parent described: "...their problem is that they can't see the work he's capable of." (ID 008).

Delayed Response. Regardless of the apparent strength of the claims or requests by parents, school and community services were often perceived as refusing formal testing before a particular age:

...and everybody else is just like, we're not going to do anything until third grade, because third grade is when you can tell, because they're still developing.” (ID 001)

Interview data suggested assessment standards vary by institution, as demonstrated by differences in the time period when assessment or professional supports may occur.

Contrasting the prior comment, another parent stated: “I was told we had to wait until grade 5. And then at grade five, there is now a very long wait list. (ID 003). As this parent eluded to, delaying service generates a backlog of children waiting to receive support, thus hindering accessibility even further.

School Unsupportive. Most parents emphasized their views on the quality of support they received through schools, it being their child’s primary support (outside of their immediate family) in most cases. Many parents commented to their child being treated similarly to typically developing students – an apparent consequence to their (the child) not being recognized as exceptional by their schools. As one parent described: “...doesn’t matter if you're seven, eight, nine or 10, we're going to cram you into a seven because that's an average of where everybody is.” (ID 001).

Those who secured their child accommodations often viewed the quality of support they (eventually) received as inadequate – either being limited in scope (i.e. addressing one of several challenges) or neglected entirely. Indeed, several parents stated that their child’s school had arranged IEPs to support their child’s challenges.

notwithstanding that the child was not formally recognized as having a LD. However, school accommodations were predominately behavioural (e.g. adjusting the child's seating in classrooms) or systemic (e.g. shortened school days). With one exception, in which the child received "modifications in language and math" (ID 007). Another parent, having demonstrated their child's needs, commented, "They've given him all the tools that I've asked for, but nobody is enforcing them." (ID 005). A minority of parents, however, expressed satisfaction with the supports their child received. As an example, one parent described feeling gratified by the school's ingenuity implementing "emotion cards" to assist their child's self-expression:

The school has incorporated cards for [son] that if he needs a time out or, you know just a break from things he can hand a card to them and they know what that means. (ID 003)

Teacher Communicative. Parents who provided more favourable reviews often referenced teachers and/or faculty (e.g. principals) specifically when expressing their contentment with school-based supports:

"So the teacher basically is going to speak to the [special education/resource teacher] and the principal and say these are what he needs. These are the changes that have to happen for grade four, whether we have a formal diagnosis or not, these are the supports that need to be put in place." (ID 010)

Financial Strain. With little support from schools, many parents relied upon community and/or professional services to address their child's needs. As shown in Table

4, most community and professional services target specific challenges – academic, behavioural, emotional or social. Consequently, parents with children affected by challenges that span multiple domains experience significant financial strain in order to support their child holistically. It is interesting and important to note that, based on the distribution of supports that had been identified, many parents were either unaware of existing supports, or unwilling to make use of them – given nearly half of these services (44%) were solely identified by a single parent.

Table 4
Supports Used Within the Current Sample

| Support Used | Participant ID |
|---|----------------|
| Academic | |
| Oxford Learning | 007 |
| Leap to Literacy | 003 |
| Learning Disabilities Association of London | 001 |
| Lexia Reading Program | 010 |
| Speech and Language Pathologist | 010 |
| Tutoring | 003, 007 |
| Behavioural | |
| Child and Youth Support Group | 010 |
| Children's Aide Society | 008 |
| Emotional | |
| Child and Youth Development Clinic | 002 |
| Psychiatrist | 010 |
| Social Worker | 003 |
| Social | |
| Onward | 010 |
| General | |
| Child and Parent Resource Institute | 008 |
| Learning Disabilities Association of London | 003, 010 |
| Pediatrician | 002, 010 |
| Parents | |
| Madame Vanier Children's Services | 010 |
| Merrymount Children's Services | 010 |
| Personal therapy | 010 |

Self-Determination Amongst Children Impacted by Learning Challenges

When asked about self-determination skills, parents expressed a wide variety of traits they perceived to be representative of their child's character – as such few concepts reached the pre-determined threshold for further analysis and interpretation ($n = 4$). The following section contains concepts that were repeated most frequently whilst parents discussed their child acting in a self-directed manner.

Psychological Empowerment. The most prominent strength – indicated by one third of parents ($n = 4$) – pertained to parent's perceptions of psychological empowerment: mainly their child's persistence. Interview data demonstrated that parent's children are capable of completing tasks in spite of repeated failure: "It amazes me at times where I'll be like, dude give it up. And he won't. And then I'm so proud of him because [it's like] I probably would have left a long time ago." (ID 005). Perseverance was apparently bolstered when tasks catered to the child's individual interests. For instance, while discussing their child's creativity, one parent (whose child displayed interest in building) stated the following:

...he used to love making those stress balls. And I would say to him [son], no more like this is your last one. We're not doing any more. That's enough. So he built this device out of like this plastic container with these hooks so that I didn't have to hold it anymore. This device would hold it and he could just fill it up and tie it... (ID 003)

Parents were far less likely to express knowledge of their child demonstrating high self-efficacy, with the exception of one parent, who eluded to their child confidence around

realizing a desired future: “He totally believes that he can do those things. If so much so that he will be crushed if they don't happen, you know.” (ID 003).

Self-Regulated Behaviour. Several concepts (identified less frequently) were conceptually related as highlighting parent’s perceptions of self-regulated behaviour – mainly problem-solving and goal setting. Two parents – whose children were affected by reading challenges – described their child generating creative solutions to (temporarily) bypass their weaknesses: one using their proficiency with technology, and the other using context cues embedded in difficult to read sentences.

She knows her own mind, so she can set out what she wants to do.

Even when she is motivated, she can figure out some of the reading – she has used some of the features on the Chromebook for example, like having the computer read to her if she really wants to figure something out. (ID 007)

She couldn't figure it out. She would just insert a word. If you read a book and you didn't know what the book was saying and you were listening and she had the book over here. Know you would think that she was reading the book perfectly, because she's inserting words. (ID 001)

Goal setting often manifest as children generating lists detailing what they believed to be the necessary steps to achieving their goals ($n = 2$):

Last few years before the season starts, he's actually written down a list of different goals and his personal goals as well as like team goals, so

he'll write down what position he wants to play and that, you know, he wants to work and help the team to get to the playoff. (ID 009)

Behavioural Autonomy. Parents opinions regarding autonomous behaviour were mostly evidenced by reports of their child's desires to engage in seemingly interesting activities ($n = 3$). For example, one parent stated: "He asked to participate in the [commercial child play centre] for the last two years...And he has asked to take on a new sport. He wants to try diving." (ID 004). When asked to provide evidence of their child's apparent interest in music, another parent simply stated: "Because he practices. Without being told." (ID 005). It is important to note that interview data is insufficient to determining the child's motivations to engage in these activities. To be considered autonomous behaviour requires intrinsic motivation (Deci & Ryan, 2000). The child would not be considered autonomous if their motivation relied upon any external influence.

Self-Realization. Self-realization was most frequently demonstrated by parents through evidence of their child's emotional intelligence. A few parents ($n = 3$) mentioned their child openly expressing anger, sadness, or worry. When describing their child's general reaction to recent news broadcasts, one parent mentioned the following: "He'll say, no, or he'll say, you know kind of indicate that, yes, he is a little bit worried about it." (ID 009). Multiple parents ($n = 2$) recalled statements their child had made that suggest them being cognizant of their challenges. Similarly, one parent demonstrated their child having knowledge of effective supports:

So she's coming to me saying, I didn't have a good day yesterday because I didn't have my meds and I was struggling. And when I'm on

my meds, I feel like I can handle these situations better. So I want to make sure that I get my meds because it makes me feel better and be better able to handle the day at school. (ID 001)

Fewer parents ($n = 2$) indicated their child showing awareness of strengths. Even so, these parents mentioned such statements being coupled with self-deprecating comments. To illustrate, one parent stated: "...he can definitely express, you know, I am good at this, but this person is better than me." (ID 010).

Promoting Independence. The aforementioned caregiving strategies (e.g. frequent prompting, maintaining routine) demonstrated the tendency of parent's to implement strategies in which their child requires scaffolding or support from their parents to meet their needs. Fewer parents utilized strategies that encourage children's independence – those who had used such strategies intended to teach their child skills that would allow them to support their future selves, including emotion-regulation skills ($n = 2$), behavioural regulation skills ($n = 2$), and empathy ($n = 1$). Particularly amongst parents with prior experience/expertise managing learning challenges, their tool-kit included psychotherapeutic techniques intended to challenge their child's negative thinking:

At the end of the night, maybe we'll lie down and I feel like I need to go over with him. Who loves him? How, what are the things he's good at so that he internalizes that a little bit. (ID 004)

Parents encouraged self-regulation through reflection – prompting their dysregulated child to reflect on factors that may have contributed to their current state:

So I always say, walk away. Put it away. We're not going to do that now. Make sure you've eaten. Make sure you've had your exercise so that you're able to come to the table. Have you had your sleep? Have you had your exercise? Have you had your meds? Have you had all these things, all these check marks to make sure that you're able to come to the table and do what you need to do. (ID 001)

One parent activated their child's perspective-taking skills under circumstances when they had behaved inappropriately towards other people. While describing a recent experience in which when their child was teasing their sibling, one parent recalled stating the following: "That's like coming up and saying, you know, [son], you can't do the work at your grade level. You're stupid. How would that make you feel?" (ID 008).

Discussion

Existing literature concerning the impact of learning challenges on school-aged children almost exclusively pertains to those who have been formally recognized as having a LD. Much less is known about the experiences of children showing early but significant learning challenges, or that of their families. To that end, this research aimed to: (a) Define the academic, behavioural, socio-emotional, familial and self-determination based needs associated with learning challenges for school-aged children and youth who had not yet received a formal diagnosis; (b) Identify community, professional, and school supports available to children affected by learning challenges in the absence of a formal diagnosis of LD; (c) Report parent's perceptions of the quality of supports and services with regards to their ability to address needs associated with their child's learning challenges.

Impact of Learning Challenges

It is commonly accepted that individuals affected by challenges with neuropsychological origins, such as a LD and ADHD experience co-occurring behavioural, socio-emotional and familial problems in addition to poor academic performance (Margari, et al., 2013). This study corroborates previous works demonstrating that children affected by learning challenges experience a range of issues across these various domains. The following section details results from standardized assessment measures and demonstrates the profound impact of learning challenges amongst children whose difficulties remain formally unrecognized. Where applicable, assessment scores are discussed in relation to results from semi-structured interviews.

Academic Challenges

With regards to parent-reported academic achievement (LDQOL/15: Academic Performance), descriptive statistics revealed that nine out of ten cases in the current sample were within at-risk or clinical range on one or more domains. Corroborating these findings, six cases were identified that would reach clinical significance with regards to reading and/or mathematics performance (using CLDQ clinical cut-off points referenced by Patrick et al., 2013)

While reviewing individual reports, it was noted that five of these cases reached clinical significance for both reading *and* mathematics performance. This finding is consistent with previous reports demonstrating significant co-morbidity rates between reading and math difficulties (Willcutt et al., 2013). Importantly, the CLDQ showed good sensitivity (but low specificity) for identifying children with LD (Patrick et al., 2013). However, it is important to note that this study instrument alone does not provide the

necessary breadth or depth of evidence required for a formal diagnosis. As such, these results should be interpreted as indicative of children with reading and math difficulties as reported by parents; not a reading and math learning disability. In accordance with evidence supporting the additive effects of mixed learning disabilities (Toffalini, Giofrè, & Cornoldi, 2017), prevalence rates for comorbid reading and mathematics difficulties likely contributes to the pronounced academic performance deficits (LDQOL/15: Academic Performance) found in the current sample.

Spelling and writing difficulties were reported by many parents in their children, but without a clinical reference group comparison available, it was difficult to assess the degree of impairment on severity in this sample. Given that learning disabilities frequently occur across a number of academic domains (Toffalini, Giofrè, & Cornoldi, 2017) and spelling and writing challenges are often present in children with LD and ADHD (Kearns D. , 2010), it would not be surprising to find a significant proportion of children also struggling in this domain within the current sample.

Behavioural Functioning

Given the high co-occurrence of LD with externalizing problems, it is also not surprising that half of parents within the current sample reported behavioural difficulties (SDQ: Conduct Problems and Hyperactivity) within the at-risk or clinically range. In the current sample, parent's often reported challenges relating to hyperactivity-inattention (e.g. distractibility, fidgety, restless: $n = 8$) relative to conduct problems (e.g. lying, ill-tempered, disobedient, aggressive: $n = 5$). Interview data suggests that the severity of Conduct Problems and Hyperactivity was often associated with children behaving uncooperatively and acting-out. These findings appear comparative to existing literature

reporting co-morbidity rates across various externalizing disorders, suggesting there being a greater likelihood of detecting ADHD-Inattentive symptoms (Carroll, Maughan, Goodman, & Meltzer, 2005) versus conduct related problems (Hendren, Haft, Black, White, & Hoefft, 2018). The prevalence of behavioural difficulties within the current sample likely explains the prominence of behavioural supports (e.g. structured reinforcements, establishing routines, frequent prompting) indicated during semi-structured interviews.

Emotional Functioning

Similarly, results from this sample indicated that parent-reported emotional problems (SDQ: Emotional symptoms) in their children reached at-risk or clinical range in six out of ten cases. Parents who rated their children rated in Emotion symptoms were more likely to express concerns with their children emotional well-being (i.e. self-esteem/self-efficacy) during semi-structured interviews. cursory comparisons across SDQ and CLDQ subscales gives the impression that Emotional symptom ratings were correlated with Math and Reading scores. These results are largely consistent with previous research demonstrating a strong association between learning challenges and internalizing symptomatology (Mugnaini, Lassi, La Malfa & Albertini, 2009). Notably, the majority of these cases fell within at-risk range ($n = 4$). This pattern is in agreement with results from Maag and Reid (2006), whose meta-analysis revealed that internalizing problems experienced by children affected by learning challenges are problematic, but infrequently reaches a level indicative of “clinical significance”.

Social Functioning

Interestingly, results related to parent's perceptions of their child's social-competence - pro-social behaviour and peer-problems (SDQ: Peer Problems and Prosocial Behaviour) – were rated (somewhat) inversely to one another. The majority of study participants ($n = 6$) reported that their child experienced peer-problems at levels indicative of borderline to clinical severity; yet, all parents indicated their child's pro-social behaviour within normal range. It is notable that that majority (83%) of parents who reported peer-problems also indicated that their child exhibited conduct problems, a pattern mirroring prior research suggesting that impaired social interactions are largely reflective of poor social information processing (i.e. the process of utilizing social information to determining appropriate emotional and behavioural decisions) amongst children affected by learning challenges (Bauminger-Zviely et al., 2019).

Family Functioning

As expected, parent's (and their families) experienced reduced levels of quality of life (LDQOL/15: Child and Family Psychological Functioning) in response to challenges associated with their child's learning difficulties. Our results substantiate recent research that parents of children with learning challenges experienced more negative emotions relative to parents of typically developing children (Silverstein, 2015). In line with Waggoner and Wilgosh (1990), our results suggest that perceptions of inadequate school supports was a major detriment to parent's emotional well-being. Within this study, this was expressed as a correspondence between ratings on LDQOL School Understanding and LDQOL Family and Child Psychological Functioning. This association is further supported by the relation between parent-reports of feeling overextended/frustrated by the

school's response to their child's learning challenges and ratings of Child and Family Psychological Functioning.

Importantly, these findings are specific to QOL problems parents perceived as resulting from their child's academic and school related difficulties (e.g. My child's school problems cause stress in our family). As such, this pattern might be further exacerbated if the LDQOL/15 instrument also considered QOL in relation to other difficulties and quality of life challenges experienced as a result of behavioural or socio-emotional difficulties.

Understanding the relationship between and across areas of challenge is necessary when planning interventions and accommodations for children with apparent learning challenges. Our findings suggest that families of children with learning challenges would benefit from holistic interventions with academic, behavioural, socio-emotional, and familial outcomes.

Caregiving Concerns for Children Impacted by Learning Challenges

Although parents were aware of the range of concerns experienced by their child (and family), a subset emerged as parent's *main concern* in caregiving – most prominently, academic (reading/writing) and emotional difficulties. Parents who prioritized their child's poor academic performance as their main concern in the interview frequently commented that academic supports provided by schools were in disagreement with parent's perceptions of their child's needs. Although many of these children were reported to display significant academic underachievement, priority was placed on children receiving a range of other supports, such as behavioural (e.g. adjusted seating) and/or systemic accommodations (e.g. modified school days). As suggested by Wilson et

al. (2007), there is a direct association between poor literacy outcomes and unmet or unaccommodated needs at school. Without early intervention and responsive supports, these difficulties often further contribute to impaired mental and physical well-being, and poorer social relationships. In addition, such discrepancies may jeopardize family-school partnerships, causing new or escalated conflicts and, by extension, negatively impacting parent's school-involvement (Lasatar, 2016). This is a dire consequence in light of the vital role of parents as advocates for their children.

Contrary to the goals and concerns of parent's, this group of parents often perceived that schools seldom responded to needs associated with their child's emotional well-being. Many of the parents in the study sample recognized and reported on their child's strengths and trusted in their ability to (eventually) reach largely expected levels of academic achievement. Consequently, many of their concerns centered around preserving their child's dignity and overall welfare. As one parent stated: "I know he will eventually learn what he needs to. I know that he will progress. But I do not want his heart broken in the process of all of this. And that is what is happening." (ID 003). Researchers have demonstrated that students affected by learning challenges who manifest maladaptive emotional profiles, specifically, low school self-esteem, are significantly more likely to experience academic underachievement (Alesi, Rappo, & Pepi, 2014). Furthermore, research in positive psychology has shown how positively activating emotions (e.g. hope, pride, enjoyment) are related to optimal educational outcomes (King & Areepattamannil, 2014). This research substantiates parent's concerns regarding their child's emotional well being, and suggests that school educators should consider whether or not classrooms are meeting children's emotional needs.

The current study undertook further investigation of individual files to explore additional details that might inform a greater understanding of parent concerns. Concerns about their child's academic (reading/writing) and emotional difficulties were exacerbated by parent's limited knowledge regarding the nature of their child's learning challenges. Although parents recognized overt weaknesses, they often could not identify the potential skills challenges contributing to their child's academic underachievement. Consequently, parents felt hindered in their ability to help or apply effective strategies. As demonstrated by previous studies (Chien & Lee, 2013), having limited knowledge about learning disabilities can undermine the ability of parents to provide their child adequate supports.

Overall, these findings suggest that parents of children with learning difficulties are often reporting a range of concerns and needs that are not currently being met through various support systems, such as those offered in school, by professional, or within existing community services. This pattern possibly adds additional credence to previous research that support systems often lack knowledge and skills necessary to support children's learning challenges and the needs that accompany them effectively (Chien & Lee, 2013): However, additional insights are required to determine the cause of such discrepancies between needs and available supports. The present findings provide a foundation for future research on parent's concerns prior to their child's learning challenges being formally recognized.

Psychosocial Support for Parents of Children Impacted by Learning Challenges

Though parents of children with learning challenges reported exhaustion – both physical and emotional – on a regular basis, few reported having psychosocial supports

available to address their own health concerns. Only a fraction of parents had received instrumental support, such as psychoeducation from mental health professionals or practical assistance with family affairs from immediate and/or extended family members. Having access to psychosocial supports is likely to reduce parenting stress and, by extension, positively impact the quality of care they provide their children (Hill & Rose, 2009). Echoing Karande, Mehta, and Kulkarni (2007), it is recommended that parents of children affected by learning challenges employ a combination of instrumental, psychological, and emotional supports to mediate tensions and anxieties related to the caregiving process.

Promoting Self-Determination in Children Impacted by Learning Challenges

Wehmeyer, Field, and Thoma (2012) define self-determined behaviour as “volitional, intentional, and self-caused, or self-initiated action” (p. 172). Self-Determination Theory (SDT) purports that optimal growth and developments requires satisfying basic psychological needs, including behavioural autonomy, self-regulated behaviour, psychological empowerment, and self-realization (Wehmeyer & Schwartz, 1997).

Interview data showed that children with learning challenges, within the current sample, appear to have some components of these psychological needs fulfilled, as demonstrated by parent’s description of examples of self-determined behaviours. Be that as it may, there were quite notable differences regarding parent’s beliefs about the relevancy of self-determination in the context of parenting/caregiving. Most parents expressed a strong desire to learn parenting strategies that would further support *their* proficiency at addressing their child’s needs. By contrast, a much smaller number were

interested in learning strategies that would bolster their child's capacity to act independently. While expecting young children to demonstrate self-determination at the same levels as adolescents or adults is unreasonable, these years of development represent a critical period for developing necessary skills that lead to self-determination in adult life (Shogren & Turnbull, 2006). According to Palmer, et al. (2012), early-childhood self-determination is frequently demonstrated by examples of self-regulation, problem solving, and engagement behaviour. As suggested by Erwin, et al. (2016), deliberate adult facilitation and scaffolded support within the home environment is essential to developing these foundational self-determination skills in young children. Research illustrates that family involvement also greatly influences, and perhaps moderates opportunities for young children to experience self-determination outside of the home (Erwin, et al., 2016). These findings are especially relevant for families of children with learning challenges, as prior literature has demonstrated that children with neurobiological disorders (e.g. ADHD) report having fewer opportunities for self-determination in classroom environments (Tannock & Rogers, 2018). Therefore, supports and accommodations – whether community, professional, or school-based – should offer family education that incorporates knowledge and skills for promoting self-determination among youth with learning challenges. Bolstering these claims, evidence exists demonstrating positive school outcomes through teaching methodologies focused on self-motivated learning and engagement, such as the Universal Design for Learning (UDL) (Capp, 2017). The UDL framework adheres to the philosophy that there are multiple ways to represent knowledge and multiple ways to demonstrate one's understanding. Further, by maximizing those opportunities, educators can increase student engagement.

To illustrate, Katz (2013) showed that a Three Block Model (TBM) of Universal Design for Learning (for details see Katz, 2012) implemented for students with diverse learning needs effectively enhanced students' perceptions of social and academic inclusiveness and autonomy. Despite growing awareness of the association between engagement and academic achievement (Skinner, Kindermann, & Furrer, 2009), there are currently few studies evaluating outcomes for such programs. Findings from this study show that supports for children with learning challenges infrequently consider self-determination as contributing to holistic care. As such, it is the authors hope that the current study will provide further incentive for ongoing investigation regarding the benefits of autonomy-supportive parenting/teaching in children with learning difficulties.

Erwin, et al. (2016) recommend family-practitioner partnerships when designing strategies to support characteristics of self-determination in children affected by learning challenges. Collaboration is necessary to account for variations in how self-determination is understood across family culture and values (Palmer et al., 2012). Self-determination, as a concept, is closely related to personal-control and independence (Shogren & Turnbull, 2006); values which are less-frequently accepted within non-European American cultures and societies (Chu, 2018). A collaborative relationship would ensure that both practitioners and educators consider the unique values and beliefs families hold regarding self-determination as it applies to children with learning challenges.

Access, Equity, and Response to Identified Needs

The learning trajectory of children is significantly affected by their early experiences (Johnson, 2017). Advancements in child development has shown that early identification and attention to the needs of children and families affected by learning

challenges can reduce or eliminate limitations in social, emotional, and cognitive functioning (High, 2008). When identification is delayed, remediation becomes more complex, and success rates lower (Ferrer, et al., 2015). This study demonstrates the pronounced nature of learning challenges during early childhood and highlights the importance of early intervention to promoting equity of treatment for children with various levels of support needs.

School systems play a vital role in promoting optimal development, especially for children who need extra support. Recently, school systems have taken an increased focus on the implementation of evidence-based practices (EBP) to improve students' academic and behaviour outcomes (Cook, Tankersley, & Harjusola-Webb, 2008). A core tenet of EBP is that instruction is designed to meet the individual needs of learners, such that it is targeted and personalized to the learner (Cook et al., 2008). This can be particularly challenging for children with disabilities, as their needs and goals are diverse, and often different from students who have not been identified with unique learning challenges (Hallahan & Kauffman, 2006). In response, some schools (especially those situated in the US) have enforced systems that elucidate and address such idiosyncrasies (Fuchs, Mock, Morgan, & Young, 2003), including responsiveness to intervention (RTI) and skills-based instructions approaches (Kearns & Fuchs, 2013). These systems, which emphasize equity of treatment for children with significant learning needs, are consistent with new perspectives that having access to quality supports is a possible human right (Ontario Human Rights Commission, 2019). Though still requiring validation within school settings, the current state of support for children impacted by learning challenges, as demonstrated here, urges consideration of such alternative approaches.

Limitations

There are several limitations worth noting. Multiple interviews were conducted weeks following the Ontario government declaring a state of emergency amid the COVID-19 pandemic. During those interviews, researchers emphasized that parents provide details pertaining to experiences/events preceding Ontario's response to the coronavirus pandemic. Regardless, interviewees could have been affected in their ability to access positively valenced memories due to the dreary-disposition brought about by structural changes in their role as caregiver amidst the current pandemic. Indeed, retrieval of episodic memories is enhanced when affective state at encoding matches that at retrieval (Weizhen & Weiei, 2018). In the current context, this could potentially bias participants' recall towards negative experiences. Consequently, results emanating from these interviews may have exaggerated parent's perceived impact of learning challenges, and reduced the generalizability of our results.

Interviews were conducted independently by two interviewers – the principal investigator and student investigator. Discrepancies in the qualitative content between interviewers suggest there may have been minor differences in how interviews were guided (e.g. the level of prompting).

Prior to data collection, authors openly acknowledged their shared perspective that support systems for children with learning challenges frequently assume (or are affected by) a deficits-based care model - one that is focused on ameliorating academic performance. This would imply that raters were more likely to exclude interview data demonstrating that services considered behavioural, socio-emotional or familial challenges. Likewise, our bias might have affected interview content by restricting the

extent of prompting following strengths-based questions, as our views presuppose that interviewees would possess greater knowledge of their child's potential weaknesses.

Being heavily invested in their child's development, it is plausible that parents within the current sample overstated their family's circumstances to goad authors into procuring additional support. Indeed, studies comparing self-reports of children and parents consistently show that parent's underestimate children's QOL (Balazs, Miklosi, Toro, & Nagy-Varga, 2016). Therefore, the results of the present study should be interpreted as possibly (unintentionally) overestimating the severity of challenges within the current sample.

Generalizability was bounded by female caregivers and male children being over-represented within this study's final sample. According to the National Alliance for Caregivers Executive Report (2009), mothers (generally) assume the primary caregiver role. It is possible that an exploration of paternal caregiving reveals divergent experiences for mothers and fathers of children with learning challenges; further research, however, is required to determine whether such differences exist. Literature concerning gender differences in the phenomenology of learning disabilities appears lacking. In light of this ambiguity, future research should include perspectives of families with school-aged females experiencing significant learning challenges also.

Concluding Statement

Research has shown how early intervention can reduce (and possibly prevent) limitations in cognitive, behavioural, and socio-emotional development that accompany children's learning challenges (Johnson, Learning Disabilities in Children: Epidemiology, Risk Factors and Importance of Early Intervention, 2017). In many circumstances,

however, these specific or intensive supports may require an official diagnosis to be considered eligible (Special Education in Ontario: The Individual Education Plan, 2017). Given delays in the availability of formal assessments, it is important that public support systems are knowledgeable of the unique (and diverse needs) that characterize this demographic. This thesis provides insight into parent's perspectives concerning substantial needs associated with managing children's learning challenges and has brought awareness to less commonly acknowledged aspects of effective care (i.e. psychosocial supports for parents; promoting self-determination). It is the hope that the results of this exploratory study will highlight opportunities for continued growth and development within systems supporting children affected by learning challenges and their families.

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Appendix A: Letter of Approval



Date: 20 January 2020

To: Dr Colin King

Project ID: 113498

Study Title: An Exploration of Needs for School-Aged Children With Suspected Learning Challenges

Short Title: An Exploration of Needs for Children With Suspected Learning Challenges

Application Type: NMREB Initial Application

Review Type: Full Board

Meeting Date: 06/Sep/2019 12:30

Date Approval Issued: 20/Jan/2020 13:33

REB Approval Expiry Date: 20/Jan/2021

Dear Dr Colin King

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMREB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

| Document Name | Document Type | Document Date | Document Version |
|------------------------------|------------------------------|---------------|------------------|
| BASC-3_PRSA | Paper Survey | 06/Dec/2019 | 1.0 |
| BASC-3_PRSA_Label | Other Document | 10/Jan/2020 | 1.0 |
| BASC-3_PRSC | Paper Survey | 06/Dec/2019 | 2.0 |
| BASC-3_PRSC_Label | Other Document | 10/Jan/2020 | 1.0 |
| BASC-3_PRSP | Paper Survey | 06/Dec/2019 | 1.0 |
| BASC-3_PRSP_Label | Other Document | 10/Jan/2020 | 1.0 |
| CLDQ | Paper Survey | 07/Oct/2019 | 2.0 |
| Demographic Information form | Paper Survey | 10/Jan/2020 | 3.0 |
| Email Draft | Recruitment Materials | 10/Jan/2020 | 3.0 |
| Email Draft CYDC | Recruitment Materials | 07/Oct/2019 | 1.0 |
| Information Summary | Debriefing document | 07/Oct/2019 | 2.0 |
| Interview_Guide | Interview Guide | 06/Dec/2019 | 2.0 |
| LD-QOL-15 | Paper Survey | 07/Oct/2019 | 2.0 |
| LOI | Written Consent/Assent | 10/Jan/2020 | 5.0 |
| Phone_Interview_V2 | Screening Form/Questionnaire | 06/Dec/2019 | 2.0 |
| Recruitment-Flyer | Recruitment Materials | 10/Jan/2020 | 3.0 |
| SDQ | Paper Survey | 06/Dec/2019 | 2.0 |
| SDQ_Label | Other Document | 10/Jan/2020 | 1.0 |

No deviations from, or changes to the protocol should be initiated without prior written approval from the NMREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB 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 NMREB is registered

with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Katelyn Harris, Research Ethics Officer on behalf of Dr. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B: General Recruitment E-mail

To whom it may concern,

Dr. Colin King, principle investigator for the study "*An Exploration of Needs for Children with Learning Challenges*", is requesting to recruit participants at your institution. The email attachment contains a recruitment flyer for distribution at your institution. These flyers contain details regarding the purpose of the study, procedures, and contact information for individuals seeking additional information.

If you have any further questions, you can feel free to contact Dr. Colin King at [REDACTED], [REDACTED], or Western's University's Office of Human Research Ethics at 519-661-3036, ethics@uwo.ca.

On behalf of the research team thank you for your assistance,

Sincerely,

Colin King, Ph.D., C. Psych



Appendix C: CYDC Recruitment Email

☐

To whom it may concern,

While providing written consent to the terms and conditions of service at the Child and Youth Development Clinic, you had indicated that you were interested in being contacted regarding participation in student education projects and/or research projects. We are now recruiting participants for the study "*An Exploration of Needs for Children with Learning Challenges*". The email attachment contains a recruitment flyer with details regarding the purpose of the study, procedures, and contact information for individuals seeking additional information.

If you have any further questions, you can feel free to contact Dr. Colin King at [REDACTED], or Western's University's Office of Human Research Ethics at 519-661-3036, ethics@uwo.ca.

On behalf of the research team thank you for your assistance.

Sincerely,

Colin King, Ph.D., C. Psych

[REDACTED] ☐
☐



Invitation to Participate in Research

An Exploration of Needs for Children with Learning Challenges

We are looking for volunteers to take part in a study to improve knowledge of the needs for children (Kindergarten - Grade 8) with learning challenges. To take part, families must suspect that a learning challenge is negatively impacting their child's academic, behaviour, or socio-emotional functioning, and have not received a formal psychological assessment of their child's learning challenges.

Children with learning challenges present with a variety of academic, behavioural, and socio-emotional challenges. This study will explore the range of needs a child might be experiencing prior to receiving a psychological assessment. However, this study is not intended to provide a formal diagnosis.

HOW IT WORKS:

As a parent or caregiver, you will be asked to take part in a 1.5 hour study taking place at the Child and Youth Development Clinic. The study will include:

- Questionnaires examining your child's learning, behaviour, or social-emotional skills
- An audio recorded interview (Note: alternatives to audio recording available)

Note: Interested parents participate in a telephone screening with a research assistant to determine eligibility prior to scheduling the study visit.

If you would like more information on this study, please contact the researcher at the contact information below.

Contact Information

Dr. Colin King
PhD, C.Psych

Version 2.0



12/06/2019

Appendix E: Screening Protocol



Phone-Interview Script

“Hi, this is (insert name) from the Child and Youth Development Clinic at Western University.

Before I can schedule you for participation, I would like to tell you a bit more about the study, as well as ask you a few questions to make sure that you qualify. Do you have 15 minutes to hear about the study?

If no: Ask for a better time to conduct the interview.

If yes:

As a participant in this study, you will be asked to take part in a series of questionnaires and interviews. Your responses will help us to understand the academic, behavioural, and socio-emotional needs your child presents with, your experiences as a caregiver, and the adequacy of services/supports you've received previously. This information is not intended to provide your child a formal diagnosis.

To start, you will be asked to provide demographic (e.g. age, sex, employment status) and contact information (e.g. home/cell-phone number, e-mail address). To protect your identity, that information will be kept on secure server only accessible to the principle and co-investigator of this study.

Following, you will complete multiple questionnaires that address your child's academic, behavioural, socio-emotional needs, and quality of life.

Afterwards, you will take part in a short interview. The interview questions will relate to perceptions of your child's needs, your experiences as a caregiver, and your experiences with supports/services accessed previously. You will also take part in a separate interview intended to gather specific information about services or supports you have already accessed to support your child's academic, behavioural, or socio-emotional needs within the past year. With your consent, this interview will be audio recorded. Alternatively, the researcher will arrange for a second interviewer to record important details from the interview manually using pen and paper.

Participation will take approximately 1.5 hours. For your time we will provide you with a summary form outlining the strengths and challenges your child presents with base on your responses. The form will also include potential resources that address your child's needs, and information on children's mental health services.

It is important to mention that your participation in this study is voluntary. It is possible for you to deny participation without any negative consequences to the quality of service you receive when accessing supports through the Child and Youth Development Clinic or elsewhere. Likewise, you may choose to withdraw or withhold information that we ask of you without any negative consequences.

Version 2.0

2

12/06/2019

Do you have any questions about this procedure? Would you still be interested in participating?"

If no:

"Thank you for your time. If you are still interested, I can refer you to supports/services available through some known local agencies, including the Child and Youth Development Clinic."

If yes:

"OK, great! Before I schedule you for an appointment, I need to ask you a few questions to make sure that you qualify. These questions will assess whether you fit within the population we are interested in for this study.

Please know that these answers will be kept confidential, and if you do not qualify for the study or choose not to participate, your answers will be destroyed and no record will be kept. Do you want to continue to the questions?"

If yes: Continue to questions.

If no: "Thank you for your time."

QUESTIONS

| | | |
|--|-----|----|
| 1. Do you suspect that a learning challenge is impacting your child's academic, behavioural, or socio-emotional functioning? | Yes | No |
| 2. Is your child currently enrolled in a local elementary school (kindergarten – grade 8)? | Yes | No |
| 3. Has your child ever taken part in a formal psychological assessment? -If yes, record details (e.g. Did they receive a formal diagnosis?) <i>Note: Parents are still considered eligible if their child been diagnosed with Attention Deficit/Hyperactive Disorder, as long as they suspect a learning challenge is contributing to their poor adaptive functioning.</i> | Yes | No |

Note: Appropriate answers are highlighted.

If the parent **does not** meet eligibility criteria: "Thank you for your time. Unfortunately, based on your responses I'm afraid you do not fit within the population we are interested in studying for this particular experiment. If you are still interested, I can refer you to supports/services available through local agencies, including the Child and Youth Development Clinic. Thank you very much for your time. If you have any further questions you can feel free to contact Dr. Colin King at [REDACTED], or Western's University's Office of Human Research Ethics at 519-661-3036.

If the parent **does** meet eligibility criteria: "Thank you for your time. It appears based on these

answers that you fit our criteria for the population we are interesting in studying. Are you still interested in participating?”

If the parent answers “yes”: “Great! When would be most convenient for you to attend the first appointment?”

Appendix F: Letter of Information



CONSENT LETTER FOR PARTICIPANTS

Study Title: An Exploration of Needs for School-Aged Children with Suspected Learning Challenges

Principal Investigator: Colin King, Ph.D., C. Psych



Invitation to Participate

I am a faculty member at the Faculty of Education at Western University and conducting a research project titled “*An Exploration of Needs for School-Aged Children With Suspected Learning Challenges*”. I am writing to invite you to be part of it.

We are recruiting parents within London, Ontario who suspect that a learning challenge is affecting their child’s academic, behavioural, or social emotional functioning or well-being. With many supports provided after a formal diagnosis of a Learning Disability, this study will examine how children are doing prior to receiving supports. The purpose of this study is to understand how receiving community, professional, and school supports may impact the overall functioning of children with suspected Learning Challenges and the experiences of parents/caregivers in caring for their child. We will meet this objective by comparing strengths, needs, and quality-of-life of children with suspected Learning Challenges, and their respective caregivers across type and quality (or intensity) of support through community, professional, and school resources/programs. This study is not intended to provide a formal assessment or diagnosis.

Procedure

- All research activities will take place at the Child and Youth Development Clinic at Western University
- Complete five paper-pencil questionnaires: Demographic Form (3 minute), Colorado Learning Difficulties Questionnaire (5 minutes), Strengths and Difficulties Questionnaire (5 minutes), Behavioural Assessment System for Children – Third Edition-Parent Rating Scale (10 minutes), and Quality-of-Life for Children and Adolescents With Learning Problems Scale (5 minutes)
- Take part in a 30 – 45 minute interview concerning perceptions of your child’s needs, difficulties with meeting your child’s needs, and the impact of supports you have already accessed to both you and your child’s well being. This will include any school related supports, including accommodations and modifications. The interview will be audio recorded, and transcribed using the TRINT transcription software. Files on TRINT’s data storage system are encrypted at-rest so that the research team is solely permitted to view those files. The resulting transcript will be reviewed promptly after they are received so as to eliminate any identifying information, and transferred to a secure server at the Child



Western Education

and Youth Development Clinic using a unique code number. At this point, a member of the research team will request TRINT permanently delete the resulting files from their data storage system. If you do not consent to using TRINT, the researcher will request that a research team member will transcribe the interview at a later time. In either case, you will be given the opportunity to review your transcript and add/remove any information at your discretion.

Confidentiality

Your identity will be kept confidential by assigning your information a unique code number. This code number will be used in place of any identifying information on all reports that result from this study. The audio recording is required for transcription purposes, and will be deleted immediately after it is transcribed. The resulting transcripts will be reviewed and edited so that no identifying information is present. You may provide researchers permission to use deidentified quotes contained within transcripts in study dissemination. If you agree, you will be given an opportunity to review the selected quotes before study dissemination. Your responses to questionnaires and transcript will be transferred to an electronic database on a secure server that is only accessible to our research team at the Child and Youth Development Clinic. Any identifying information will be kept in a secure location at the Child and Youth Development Clinic. Identifiable information, including telephone number and email address, will be stored on a master list in a secure location at the Child and Youth Development Clinic, accessible only to the principal investigator and co-investigator. Participants will be asked to indicate their home address and postal code directly on the envelope which will be used to deliver an information summary report. Therefore, this information will not be collected and maintained in study records.

Telephone number and/or email address will be used to contact participants if the researcher experiences difficulties with delivering the information summary form directly to the participant's home address. Email address will also be used to provide a link to a shared google drive that will contain non-identifying handouts/resources that may benefit caring for your child. The information will be retained for 7 years following study completion, at which point it will be permanently deleted, in accordance with Western University's Research Ethics policy. Representatives of the University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

We might be placed in a responsibility/duty to report if you disclose that you were aware of your child's expression of suicidal intent, but had not responded or acted in a responsible, immediate manner to these concerns (e.g., had not looked at support for the child; was aware of the intent, but did nothing to prevent/respond to these concerns; or the expression of suicidal intent was immediate and the child/youth was in imminent harm). If it is determined that you were unresponsive to this expression of suicidal intent, we might be required to report this information to the appropriate authorities.

Risks/Benefits

During the interview, you may be asked to discuss topics that are uncomfortable. This may result in a mild form of distress.



For your participation, you will be offered a summary form containing relevant information to caring for children with learning challenges. This form will also include a summary of your child's strengths and challenges according to your responses to the study questionnaires and interviews. These supports and resources may be helpful in supporting your child at school and at home.

This information summary was prepared for parents and caregivers participating in a research project on students experiencing learning challenges at school. This information summary is for information purposes only and is not intended to provide specific or diagnostic information or to replace in-depth assessment practices.

The results of this study will provide insight regarding the type and intensity of support that provide the greatest conceivable benefit in addressing children's academic, behavioural and socio-emotional, fostering children's strengths, and improving quality-of-life for children and their families. Consequently, the current study may assist in reforming disability policy to provide a greater quality-of-care for children with suspected Learning Challenges and their care providers.

Publication of Results

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available once the study is complete (estimated: April 2020) by contacting Dr. Colin King at the address or phone number listed in "For Additional Information". Only information about the results of the entire study will be available, not information on individual responses.

Voluntary Nature of Research

You may withdraw your participation at any time without any negative consequences. You will also have the option to withdraw any information that has been collected without negative consequences. Likewise, you have the right to withhold your responses to questionnaire or interview questions. Furthermore, no new information will be collected without your permission. You do not waive any legal rights by signing this consent form. We will provide you any new information that may affect your decision to stay in the study when it becomes available.

For Additional Information

This letter is yours to keep for future reference. If you would like more information about this project, or your role in it, please contact me by phone [REDACTED] or by email [REDACTED]. Concerns about your participation in this study can be forwarded to Western University's Office of Human Research Ethics at 519-661-3036, ethics@uwo.ca.

Please complete the attached form and return it to the research assistant.

Sincerely,
Colin King, Ph.D., C.Psych



Study Title: An Exploration of Needs for School-Aged Children with Suspected Learning Challenges

Principal Investigator: Colin King, Ph.D., C. Psych



I have read the attached Letter of Information regarding the study entitled, “An Exploration of Needs for School-Aged Children with Suspected Learning Challenges”. All questions have been answered to my satisfaction.

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research. Yes No

I consent to the using TRINT’s automated-transcription software for transcribing audio recordings. Yes No, I prefer to have a research team member transcribing the audio recording.

I would like to receive a summary of the research results Yes No

Name of parent/caregiver: _____

Signature: _____

Date: _____

Name of witness: _____

Signature: _____

Date: _____



My signature means that I have explained the study to the participant named above. I have answered all questions.

Name of researcher: _____

Signature: _____

Date: _____

Appendix G: Interview Guide

Interview Guide for Parents of Children with Learning Difficulties

The following was designed for parents of children with learning challenges. Questions concern needs of parents, and details of supports received previously through school, community, and professional services. The interview will be audio recorded, and transcribed using an online automated transcription software. For confidentiality reasons, we ask that you avoid using identifiable information during this interview.

| Questions | Probing |
|--|---|
| 1. In caring for your child with learning challenges, please describe to me: * | |
| <input type="checkbox"/> Your everyday caregiving to the child: | <ul style="list-style-type: none"> ○ Personal hygiene & cleanliness ○ School & after school studying ○ Leisure & family activities ○ Other learning or social activities |
| <input type="checkbox"/> What you know about the nature of the challenges that your child experiences: | <ul style="list-style-type: none"> ○ Diagnosis, nature & characteristics, & treatment ○ Main illness & behavioral characteristics ○ Your feelings & thoughts when you learned the diagnosis |
| <input type="checkbox"/> What you think and feel about caring for the child: | <ul style="list-style-type: none"> ○ Your feelings in the first few months as you learned more about the illness & the caregiving required ○ Your current feelings & thoughts |
| 2. What did you expect to know about taking care of your child? * | <ul style="list-style-type: none"> ○ The nature of the challenges your child faces & treatment ○ Daily care ○ Academic performance ○ Self care & family affairs |
| 3. What are your main concerns in caregiving? * | <ul style="list-style-type: none"> ○ Physical & illness aspects ○ Psychological & emotional aspects ○ Family & social aspects |
| 4. Please describe one or two recent experiences of childcare that have made the deepest impression. * | <ul style="list-style-type: none"> ○ Health & well being ○ Work ○ Recreation & activities ○ Family & social relationships |
| <input type="checkbox"/> Referring to these experiences, what challenges or difficulties did you encounter in caregiving? | |
| <input type="checkbox"/> How did you handle such difficulties or challenges? Please illustrate your ideas with examples. | |
| 5. If applicable, please describe one or more recent examples and/or events related to the following: | <ul style="list-style-type: none"> ○ My child get's along well with others ○ My child seeks out social contact ○ I am knowledgeable/familiar with my child's social group ○ My child expresses feeling loved or cared for ○ Other children treat my child kindly ○ My child expresses admiration for others |
| 6. Please describe one or more recent events during which your child had demonstrated the following characteristics (with family, school, friends, etc.) | |

Behavioural autonomy ^a

- Performs routine personal care (e.g. care for clothing, grooming, preparing snacks or meals, caring for or organizing personal items)
- Engages in family oriented functioning (e.g. chores, care of possessions)
- Fulfills responsibilities
- Participated in recreational or social activities that reflect the child's values, interests, or abilities
- Expresses their personal style through personal items, clothes, hair, decoration, or gifts
- Makes friends with children their age

Self regulated behaviour ^b

- Goal setting
- Self-management (e.g. self-monitoring, self-instruction, self-evaluation, self-reinforcement)
- Problem solving
- Decision making
- Choice making

Psychological Empowerment ^c

- Expresses their opinions
- Self-efficacy (i.e. the belief that they can accomplish a specific task)
- Outcome expectancy (i.e. the expectation that their actions will contribute to a desired outcome)
- Persistence when faced with adversity

Self realization ^d

- Awareness of strengths
- Awareness of limitations
- Awareness & expression of feelings
- Self-acceptance (e.g. admiring themselves, accepting their feelings, accepting their strengths & limitations)

7. Are there any aspects of your experience as a caregiver (e.g. responsibilities, your child's behaviour) that has not been addressed by the previous questions?

Notes. *Original interview protocol provided by Chien, W., & Lee, I. Y. M. (2013).

All definitions are adapted from descriptions provided by Wehmeyer (1995).

^a *Behavioural autonomy* is defined as acting in a self-directed manner according to one's values, interests, or abilities.

^b *Self-regulated behaviour* is defined as a decision making process whereby the individual monitors, evaluates, and revises their actions according to their satisfaction with the outcome of their actions, environmental demands, and resources available for coping with the environment.

^c *Psychological empowerment* is defined as an individual's belief in their ability to affect their circumstances, having the skills required to do so, and the expectation that their actions will produce the preferred outcome.

^d *Self realization* is defined as having an accurate understanding of one's strengths and weaknesses, and to act with the intention of utilizing that knowledge.

Appendix H: Demographics Form



Demographic Information Form

Instructions: Please provide a response for each of the following questions:

ID: _____ Date: _____

1. What is your age? _____

2. What is your gender?

Prefer not to specify

3. What is your marital status?

Prefer not to specify

4. What is your employment status?

Prefer not to specify

5. With which racial or ethnic category do you identify?

Other: _____

6. With what denomination or faith tradition do you most closely identify with?

7. What is your highest level of education achieved?

Prefer not to specify

8. What is your child's first name?

9. What is your child's age? _____

10. What is your child's gender?

Prefer not to specify

Appendix I: Information Summary Form

Information Summary

ID:

Participation Date:

This information summary was prepared for parents and caregivers participating in a research project on students experiencing learning challenges at school. This recommendation summary is for information purposes only and is not intended to provide specific or diagnostic information or to replace in-depth assessment practices.

STRENGTHS:

CHALLENGES:

Recommendations and Supports:

1. Sample academic resources that may be helpful can be found at:

www.understood.org (Understood – For Learning and Attention Issues)
www.ldathome.ca (LD @ Home)
www.ldaschool.ca (LD @ School)
www.readingrockets.org (Reading Rockets)
www.ldao.ca (Learning Disability Association of Ontario)
www.nclld.org/ (National Centre for Learning Disabilities)
www.fcrr.org/resources/resources_sca.html (Florida Center for Reading Research)
www.parenttoolkit.com/ (Parent Toolkit)
www.ldalondon.ca (Learning Disability Association of London)
www.tvdsb.ca/en/programs/special-education.aspx (Thames Valley District School Board – Special Education)
www.ldcsb.ca/Programs/specialeducation/Pages/default.aspx (London District Catholic SchoolBoard-Special Education)

2. Sample information and resources on family supports and children’s mental health can be found at:

<http://www.vanier.com/resources.aspx> (Vanier Children’s Services)
<https://wellkin.ca/resources/> (Wellkin Child and Youth Mental Wellness)
<https://www.lhsc.on.ca/child-and-adolescent-mental-health-care-program> (Child and Adolescent Mental Health Care Program)
<https://www.miunderstanding.ca/p-i-p-e-program/> (Parents in Partnership with Education – M.I. Understanding)
<https://www.sickkidscmh.ca/abc/welcome> (SickKids - ABC’s of Mental Health)
<https://psychologyfoundation.org/> (Psychology Foundation of Canada)

Appendix J: CLDQ

Colorado Learning Difficulties Questionnaire

| | |
|-----|-------|
| ID: | Date: |
|-----|-------|

Please circle the most appropriate number for each statement that corresponds most closely to your desired response.

| Does/did your child ever have... | <i>Never / Not at All</i> | <i>Rarely / A Little</i> | <i>Sometimes</i> | <i>Frequently / Quite a Lot</i> | <i>Always / A Great Deal</i> |
|---|-------------------------------|------------------------------|------------------|-------------------------------------|----------------------------------|
| 1. Difficulty with spelling | 1 | 2 | 3 | 4 | 5 |
| 2. Difficulty learning letter names | 1 | 2 | 3 | 4 | 5 |
| 3. Difficulty learning phonics (sounding out words) | 1 | 2 | 3 | 4 | 5 |
| 4. Read slowly | 1 | 2 | 3 | 4 | 5 |
| 5. Read below grade or expectancy level | 1 | 2 | 3 | 4 | 5 |
| 6. Required extra help in school because of problems in reading and spelling | 1 | 2 | 3 | 4 | 5 |
| 7. Poor understanding of interpersonal space | 1 | 2 | 3 | 4 | 5 |
| 8. Difficulty knowing how others are reacting | 1 | 2 | 3 | 4 | 5 |
| 9. Has trouble understanding how others are feeling | 1 | 2 | 3 | 4 | 5 |
| 10. Makes comments that show a lack of understanding of social situations, such as inappropriate jokes or insensitive remarks | 1 | 2 | 3 | 4 | 5 |
| 11. Difficulty making or keeping friends | 1 | 2 | 3 | 4 | 5 |
| 12. Isolates self in social situations | 1 | 2 | 3 | 4 | 5 |
| 13. Feels anxious or out-of-place in new social situations | 1 | 2 | 3 | 4 | 5 |
| 14. Handwriting is spatially disorganized | 1 | 2 | 3 | 4 | 5 |
| 15. Papers look disorganized or messy | 1 | 2 | 3 | 4 | 5 |
| 16. On arithmetic problems, has difficulty keeping the numbers lined up in columns | 1 | 2 | 3 | 4 | 5 |
| 17. Drawings look immature for her/his age | 1 | 2 | 3 | 4 | 5 |
| 18. Worse at math than at reading and spelling | 1 | 2 | 3 | 4 | 5 |
| 19. Makes careless errors in math, such as adding when the sign indicates subtraction | 1 | 2 | 3 | 4 | 5 |
| 20. Trouble learning new math concepts such as carrying or borrowing | 1 | 2 | 3 | 4 | 5 |

Willcutt EG, Boada R, Riddle MW, Chhabildas N, DeFries JC, Pennington BF. Colorado Learning Difficulties Questionnaire: validation of a parent-report screening measure. *Psychological Assessment*. 2011;23(3):783, 788.

Quality-of-Life in Children and Adolescents With Learning Problems

| | |
|-----|-------|
| ID: | Date: |
|-----|-------|

Please circle the most appropriate number for each statement that corresponds most closely to your desired response. Please give your answers on the basis of your child's behaviour over the past 6 months.

| | <i>Never</i> | <i>Sometimes</i> | <i>Often</i> | <i>Most of the time</i> |
|---|--------------|------------------|--------------|-------------------------|
| 1. I worry about my child's academic progress | 1 | 2 | 3 | 4 |
| 2. My child takes longer to complete homework than his/her peers | 1 | 2 | 3 | 4 |
| 3. My child completes his/her homework independently | 1 | 2 | 3 | 4 |
| 4. My child independently completes work at school | 1 | 2 | 3 | 4 |
| 5. We limit family activities so that my child can complete homework | 1 | 2 | 3 | 4 |
| 6. My child worries about school work | 1 | 2 | 3 | 4 |
| 7. My child lets out frustrations about school when he/she comes home | 1 | 2 | 3 | 4 |
| 8. My child is frustrated by schoolwork | 1 | 2 | 3 | 4 |
| 9. My child's school problems cause disagreements in our family | 1 | 2 | 3 | 4 |

| | <i>Strongly Agree</i> | <i>Agree</i> | <i>Disagree</i> | <i>Strongly Disagree</i> |
|---|-----------------------|--------------|-----------------|--------------------------|
| 10. I am satisfied with my child's educational program | 1 | 2 | 3 | 4 |
| 11. My child's teachers understand his/her learning needs well | 1 | 2 | 3 | 4 |
| 12. My child's teachers know how to make him/her feel successful | 1 | 2 | 3 | 4 |
| 13. My child's homework is appropriate for his/her learning abilities | 1 | 2 | 3 | 4 |
| 14. My child does well socially in school | 1 | 2 | 3 | 4 |
| 15. My child's school problems cause stress in our family | 1 | 2 | 3 | 4 |

Waber, D. P., Boiselle, E. C., Forbes, P. W., Girard, J. M., & Sideridis, G. D. (2018). Quality of Life in Children and Adolescents With Learning Problems: Development and Validation of the LD/QOL15 Scale. *Journal of Learning Disabilities*, 002221941877511. <https://doi.org/10.1177/0022219418775119>

Appendix L: SDQ

Strengths and Difficulties Questionnaire

P 4-10

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behavior over the last six months.

Your child's name

Male/Female

Date of birth.....

| | Not True | Somewhat True | Certainly True |
|---|--------------------------|--------------------------|---------------------------|
| Considerate of other people's feelings | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Restless, overactive, cannot stay still for long | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often complains of headaches, stomach-aches or sickness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Shares readily with other children, for example toys, treats, pencils | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often loses temper | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Rather solitary, prefers to play alone | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Generally well behaved, usually does what adults request | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Many worries or often seems worried | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Helpful if someone is hurt, upset or feeling ill | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Constantly fidgeting or squirming | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Has at least one good friend | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often fights with other children or bullies them | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often unhappy, depressed or tearful | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Generally liked by other children | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Easily distracted, concentration wanders | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Nervous or clingy in new situations, easily loses confidence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Kind to younger children | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often lies or cheats | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Picked on or bullied by other children | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often offers to help others (parents, teachers, other children) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Thinks things out before acting | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Steals from home, school or elsewhere | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Gets along better with adults than with other children | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Many fears, easily scared | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Good attention span, sees chores or homework through to the end | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Appendix M: Code Descriptions

| Code Label | Description |
|---------------------------------|---|
| Information Unknown | Demonstrates gaps in parent's knowledge regarding their child's learning challenges |
| Parent Unprepared | Demonstrates uncertainty regarding best practices for managing challenges their child experiences. |
| Lack Understanding | Demonstrates uncertainty regarding the nature of their child's learning challenges. |
| Gathering Information | Demonstrates the means through which parent's gathered information regarding the nature of their child's learning challenges and/or parenting strategies. |
| Conducting Research | Knowledge accrued through conducting research. |
| Communicating with Teachers | Reaching out to teachers to inquire about their child's behaviour/performance. |
| Prior Experience | Knowledge stems from prior experience (through education, work experience, or working with other child). |
| Information Known | Demonstrates parent's knowledge of the nature of their child's learning challenges and appropriate parenting strategies. |
| Aware of Individual Differences | Parent demonstrates awareness of idiosyncrasies related to caregiving for their child. |
| Aware of Discrepancy | Parent demonstrates awareness of discrepancy between child's capabilities and academic performance. |
| Capable of Doing Work | Parent demonstrates that their child is capable of completing assigned tasks with adequate supports (e.g. intrinsic/extrinsic motivators) |
| Early Identification | Parent eludes to knowing about potential learning challenges early in their child's development (i.e. prior to a formal diagnosis) |
| Behavioural Concerns | Demonstrates parent's concerns regarding behavioural functioning. |

| | |
|---|--|
| Acting Out Behaviour | Child acts inappropriately when experiencing discomfort. |
| Child Uncooperative | Child intentionally ignores/disobeys rules assigned by others. |
| Emotional Concerns | Demonstrates parent's concerns regarding emotional functioning. |
| Low Self-Esteem | Child holds a generally negative view of self. |
| Poor Self-Efficacy | Child perceives themselves as incapable of functioning adequately. |
| Child Overwhelmed by School | Child returns from school exhausted/school challenges child beyond their ability to cope effectively. |
| Child Frustrated | Child experiences frustration in response to difficulties overcoming their weaknesses. |
| Social Concerns | Demonstrates parent's concerns regarding social functioning. |
| Teased by Others | Child experiences ridicule from peers. |
| Cognitive Concerns | Demonstrates parent's concerns regarding cognitive skills. |
| Poor Attention | Child experiences difficulty remaining focused on a specific task. |
| Challenges of Caregiving | Demonstrates challenges that parents face when supporting their child with learning difficulties. |
| Feeling Frustrated | Parent experiences frustration in association with their responsibilities caring for their child. |
| Feeling Overextended | Parent comments to excess of responsibilities assigned to caregivers. |
| Balancing Needs of Child | Parent comments to difficulties meeting various needs associated with their child's challenges. |
| Homework Assistance | Parent comments to time spent assisting child with homework assignments. |
| Managing Family | Parent comments to efforts in managing interactions between family members. |
| Supporting Children Impacted by Learning Challenges | Demonstrates knowledge of parenting/teaching strategies for supporting their child with learning challenges. |

| | |
|--|---|
| Establishing Routine | Child is provided a routine that grants consistency in their day-to-day activities. |
| Frequent Prompting | Child is provided frequent prompting to remain on task. |
| Maintain Structure | Child is given firm rules to manage transitions between tasks. |
| Supporting Emotional Regulation | Child required support with emotional well-being to compensate for limited coping mechanisms. |
| Supporting Parents of Children Impacted by Learning Challenges | Demonstrates supports available for parents of children with learning challenges. |
| Sharing Responsibilities | Parent share responsibilities of caring for child/parent shares household chores with other family members. |
| Accessing Supports | Demonstrates parent's experience when accessing supports for their child with learning challenges. |
| Delayed Response | School system chooses to hold-off on providing supports until the child "fully develops". |
| Difficulty Acquiring Support | Parent comments to difficulties experienced demonstrating need for supports. |
| School Unsupportive | Parent experiences school support as inadequate. |
| Financial Strain | Parent comments to financial burden associated with acquiring support. |

Curriculum Vitae

NAME: Joseph Capozza

EDUCATION

Masters of Counselling Psychology, Faculty of Education September 2018 - Present
Western University, London, Ontario

Honours Bachelor of Arts, Psychology, Co-op September 2012 - October 2016
Brock University, St. Catharines, Ontario

RELEVANT EXPERIENCE

Career Counselling Intern at Careers & Experience September 2019 – May 2020
Western University, London, Ontario

Group Facilitator for Strengthening Families Program January 2020 – March 2020
Muslim Resource Center, London, Ontario

Group Facilitator for HEAL Program July 2019 - August 2019
St. Joseph's Hospice, London, Ontario

Research Coordinator May 2017 - September 2018
Brock University, St. Catharines, Ontario

Research Assistant September 2016 - June 2017
St. Joseph's Hamilton Healthcare, Hamilton, Ontario

Research Assistant May 2016 - June 2017
St. Joseph's Healthcare Hamilton, Hamilton, Ontario

HONOURS AND AWARDS

Dean's Honours List
2012 – 2015

Returning Scholars Award
2012 – 2015

June Callwood Outstanding Achievement Award for Volunteerism
2015

Natural Sciences and Engineering Research Council (NSERC) Grant
2014