

SCHOOL FACTORS IN RELATION TO QUALITY OF LIFE FOR CHILDREN WITH
SEVERE DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

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Abstract

Children with severe developmental disabilities (DD) are frequently excluded from research and little is known about their quality of life (QoL). Schools have integral roles in children's lives. The present study sought to understand how school-related factors impact QoL for children with DD and their families. 171 parents of children with DD completed questionnaires about their children, themselves, their community, and their child's school. Hierarchical multiple regression analyses were performed to understand the impact of these factors on child and family QoL. 123 parents responded to an open-ended question about their children's education experiences and responses were analysed qualitatively. School satisfaction predicted QoL for both children and their families, over and above all other variables examined. Thus, there is not one single educational strategy that improves QoL for children with DD. Rather, QoL is positively impacted when strategies implemented are deemed by parents as meeting the needs of their children.

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Introduction

The purpose of this study was to examine the relationships between school-related variables and quality of life (QoL) for children with developmental disabilities (DD) and their families. Individuals with DD have significant difficulties with intellectual and adaptive functioning which present during childhood and/or adolescent developmental periods. QoL for children with DD has only been minimally investigated in previous research. Additionally, there is a lack of clarity in how school factors might impact QoL for parents and families of children with DD. The need to explore the relationships between these variables was the motivation for the current study.

Theoretical Foundation

This study was founded on the principles of Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1979). This framework indicates that psychological development is shaped by an interconnected system of relationships, roles, activities, and settings. Therefore, when studying child development, we must consider not only the child and their immediate surroundings, but also the interactions that take place throughout the broader environment. Ecological Systems Theory identifies five levels of environmental influence (Shelton, 2018). The first level is the microsystem which includes individuals with whom a child has direct contact in their immediate environment (e.g., parents, siblings, and friends). The second level is the mesosystem which accounts for interactions between the individuals in a child's microsystem that can directly affect the child (e.g., a positive relationship between a child's parent and their teacher). The exosystem includes formal and informal social structures that have indirect effects on a child because they influence the microsystem (e.g., schools, parental workplaces, media). The macrosystem accounts for cultural dynamics that may influence a child (e.g., socioeconomic

status, geographic location, religion). The final level is the chronosystem which is made up of changes and transitions that occur over time (e.g., growing older, changing schools, moving; Shelton, 2018).

For this study, aspects of the microsystem that we were particularly interested in were the child's family, teachers, school support staff, and classmates. Elements from the exosystem that may have impacted our participants could have included organizations such as school divisions, school boards, and the Ministry of Education. Some possible influential components from the macrosystem include educational ideologies and attitudes toward disability. Influences from the chronosystem could have included progressing through different grades, switching schools, and changing teachers. The mesosystem was also an integral aspect of our study as interactions between individuals at all these levels had the potential to greatly influence the lives of our participants.

For the purpose of our research, we sought to acknowledge that processes at all levels of the Ecological System impact individual children and their families. As such, we obtained measures of variables from each level. The specific outcomes that we were interested in were Child Quality of Life (CQoL) and Family Quality of Life (FQoL). Our analyses were designed to reflect the structure of the Ecological System. We had a particular interest in whether the school-related variables would predict CQoL and FQoL over and above variables at other levels.

Review of Literature

Developmental Disability

Developmental disability (DD) refers to a combination of developmental, cognitive, and adaptive functioning difficulties which may be related to different degrees of neurological and physical impairment (Sigafoos et al., 2020). DDs are lifelong conditions that exist from birth or

early childhood. They may first be recognized based on significant delays in attaining early developmental milestones such as walking, talking, feeding, and toileting (Sigafos et al., 2020). These delays are a result of children with DD learning more slowly and with greater difficulty than their typically developing peers. Intellectual and adaptive functioning must be assessed to diagnose someone with a DD. On formal assessments of cognitive functioning, an IQ at or below 70 indicates significant deficits in intellectual functioning (American Psychiatric Association, 2022). These deficits can be associated with reasoning, problem solving, planning, abstract thinking, and judgement. Adaptive functioning refers to age-appropriate and independent skills and behaviours. These include, but are not limited to, communication abilities, social skills, and self-care efficacy (American Psychiatric Association, 2022). Higher levels of adaptive behaviour are associated with lower severity of support needs (Simões et al., 2016). In other words, greater adaptive functioning may result in greater independence. Conditions that are frequently associated with DD include autism spectrum disorder (ASD), down's syndrome, cerebral palsy, spina bifida, and epilepsy (Sigafos et al., 2020). Someone with DD may also present with several co-occurring conditions.

Many individuals with DD may never achieve independence or proficiency in certain crucial domains of functioning (Sigafos et al., 2020). This is likely, in part, due to the high prevalence of co-occurring conditions and challenges these individuals face. Some studies have found that up to 50% of children with DD also have mental health disorders (Einfeld et al, 2011; Sigafos et al., 2020). These may include, but are not limited to, anxiety, depression, phobias, and obsessive-compulsive disorder. Additionally, higher severity of DD is associated with increasing frequency of challenging behaviours (Matson & Rivet, 2008). Challenging behaviours (e.g., aggression, destruction, stereotypy, self-injurious behaviour, and disruptive behaviour)

increase difficulties in accessing effective education, living accommodations, and socialization throughout the lifespan.

Frequently associated with challenging behaviours are sleep difficulties, which occur at a much higher rate in children with DD than in typically developing children. In fact, researchers have found that over 70% of children with severe DD experience difficulties with falling asleep, staying asleep, and getting a sufficient amount of sleep (Richdale et al., 2000). Bedwetting, breathing difficulties, nightmares, and hyperactivity can all contribute to disruptions in sleep (all of which occur more frequently with higher DD severity; Richdale et al., 2000). These challenges also cause high levels of stress in caregivers and families which can have further implications. In fact, research has found that DD can be a risk factor for adverse childhood experiences related to parental and familial circumstances. Children with DD may experience increased occurrences of child maltreatment and parent mental illness, divorce, and substance use (Berg et al., 2019). Families of children with DD also face increased instances of poverty in comparison to families of children without DD (Berg et al., 2019). Suffice to say children with DD are a complex and vulnerable population who face many additional challenges.

Education and Disability Severity

Over the past several years, education systems across Canada have adopted inclusive education policies for integrating children with DD into mainstream schools and classrooms (Ontario Ministry of Education, 2009). One purpose of inclusive education is to facilitate the development of quality relationships between children with DD and their typically developing peers (Webster & Carter, 2013). In Ontario, inclusive education is explicitly outlined as the development of spaces where “students see themselves reflected in their curriculum, their physical surroundings, and the broader environment” (Ontario Ministry of Education, 2009, p.

68). While this is done with the best of intentions and it sounds beneficial, in theory, research indicates it is not necessarily effective (Bhopti et al., 2020; Kurth et al., 2020; Perry et al., 2020; Webster & Carter, 2013). When applied appropriately, there are great benefits to including children with DD in mainstream schools and classrooms (Carrington et al., 2016; Ruijs & Peetsma, 2009; Simón et al., 2022; Webster & Carter, 2013). However, inclusion does not simply refer to a child's physical presence in the same classroom as other children and executing it as such is not effective (Dillenburger, 2012; Ruijs & Peetsma, 2009).

It is typically necessary for children with DD to be provided with individualized education plans (which may involve collaboration between educational staff and a variety of other disciplines such as speech and language pathology, occupational therapy, and applied behaviour analysis; Sigafos et al., 2020). While these academic accommodations can be implemented in an inclusive classroom, the success of implementation relies on the knowledge, expertise, and resources of the educational staff (Dillenburger, 2012). Unfortunately, many teachers do not feel that they are equipped with the necessary resources or supports to successfully employ inclusive education policies for children with severe DD (Carrington et al., 2016). Significant challenges identified by teachers included augmented time constraints and additional obligations as well concerns about the impacts of challenging behaviours on other students. While some children's needs can be met by additional support from general education teachers within regular classrooms, others may require individual educational assistants, specialized classrooms, or special school placements (Dillenburger, 2012).

Parents of children with DD tend to feel more supported by specialized school programs than general education settings (Bhopti et al., 2020). These parents also report lower satisfaction with mainstream classrooms than specialized classrooms (Perry et al., 2020). A thematic analysis

of parent perceptions on their involvement in their children's education intervention plans revealed that parents felt they had a lack of choice in making educational decisions and that they needed to fight for supplementary assistive services for their children within schools (Kurth et al., 2020). Some research has shown that parents of children with DD report that dealing with schools and support services is the greatest challenge they face (Kerr et al., 2023). Overall, parents of children with DD seem to be dissatisfied with schools but experiences are highly variable, and it is recognized that this satisfaction can fluctuate across time and circumstance (Kurth et al., 2020).

In a study on the impact of symptom severity in children with ASD on caregiver school satisfaction, it was found that more severe symptoms were associated with lower parental satisfaction with schools (Vohra et al., 2014). This may be because parents of children with more severe symptoms feel the amount of special education and assistive services offered are inadequate for what their children require and these parents expect higher levels of qualification, training, and skill from educational personnel than do caregivers of children with lower severity (Vohra et al., 2014). Additionally, the number of co-occurring disabilities in a child has been associated with an increased level of parental dissatisfaction with school placements and school communication (Zablotsky et al., 2012). Co-occurring psychiatric conditions have also been associated with worse school adjustment among children with ASD (Schneider et al., 2022). This is particularly concerning because research has shown that the prevalence of co-occurring conditions among individuals with DD has been found to be significantly higher than in the general population (e.g., anxiety disorders, affective disorders; Einfeld et al, 2011; El Mrayyan et al., 2019; Sigafos et al., 2020). Children with adequate levels of adaptive behaviours (i.e., less severe DD) have also been known to demonstrate better improvement in challenging behaviours

and faster academic improvement and adjustment to school settings over the course of the school year (Schneider et al., 2022). Parent positivity, child adaptive skill level, and type of classroom placement have also been demonstrated to significantly predict school satisfaction (Perry et al., 2020). The challenges that a child experiences in adjusting, the challenges that parents face in supporting a child with DD, and the capacity of the school system to provide intensive supports (when needed) all impact parental satisfaction with educational experiences. It is unclear whether this satisfaction (or lack thereof) may impact other aspects of life (such as QoL) for these families.

Quality of Life

The concept of QoL was developed as a way of assessing an individual's overall wellbeing. The core factors that make up QoL are material, physical, and emotional wellbeing, personal development, self-determination, interpersonal relationships, social inclusion, and rights (Heras et al., 2021). QoL is influenced by both internal and external factors and may include a combination of components that are objective (e.g., income and job status) and subjective (e.g., feelings about personal success and relationships). It has been found that the factors which make up QoL for the general adult population are also applicable to individuals with DD (Petry et al., 2005). The concept of QoL is particularly relevant when considering these individuals. In fact, the concept is so important that there is a separate branch concerned with evaluating the overall wellbeing of family units that specifically include one or more member with DD: FQoL. The components that make up FQoL are family interaction, parenting, emotional wellbeing, physical and material well-being, and disability-related support (Hoffman et al., 2006). Research has shown that QoL for individuals and families can be impacted by a variety of factors including age (Ncube et al., 2018; Vos et al., 2010), adaptive skills (Balboni et al., 2020; Simões et al.,

2016), co-occurring conditions (Leader et al., 2021; Ncube et al., 2018), caregiver wellbeing (Feng et al., 2022; Lei & Kantor, 2022; Ncube et al., 2018; Wang et al., 2022), social support (Cai et al., 2023; Hassanein et al., 2021; Lei & Kantor, 2022; Wang et al., 2022), socioeconomic status (Knorst et al., 2021), community size (Helliwell et al., 2019; Maier & Kim, 2008), and education satisfaction (Ncube et al., 2018). Regardless of the person or people for whom it is applied, QoL is based upon both “common human experiences and unique, individual life experiences” (Petry et al., 2005, p. 44).

Research on CQoL is lacking and research on children with severe DD is even scarcer (Ncube et al., 2018). In fact, to the best of our knowledge, only one study has examined individual CQoL for children with severe DD. Although it must be noted that individuals with severe DD frequently have limited capabilities to complete self-report measures, it is a disservice to simply disregard these individuals because of this challenge. Ncube and colleagues (2018) conducted the aforementioned study on CQoL (utilizing a sample overlapping with that of the present study) wherein parents provided their personal perceptions of their children. They found that the strongest individual predictor of CQoL was education satisfaction (Ncube et al., 2018). However, their measure of education satisfaction was a single item (“overall, how satisfied are you with the quality of your child’s education?”). This leaves this topic needing to be explored further. There are several aspects of the school environment (e.g., type of classroom placement, level of specialized services offered within schools, and parental satisfaction with schools) that might specifically impact QoL. In addition to negatively affecting education satisfaction, increased symptom severity and greater number of co-occurring conditions in individuals with DD can negatively impact QoL (Leader et al., 2021; Ncube et al., 2018). Unfortunately, families caring for children with DD report significantly lower levels of satisfaction with their health,

financial wellbeing, family relationships, social support systems, careers, education, leisure activities, community involvement, and enjoyment of life in comparison to families of children without DD (Brown et al., 2006).

Higher levels of support from others have been found to considerably increase FQoL (Cai et al., 2023; Hassanein et al., 2021; Lei & Kantor, 2022; Wang et al., 2022). In one study, social support and support from services were identified by parents as being the most influential aspects of FQoL (Steel et al., 2011). Indeed, caregivers of children with severe DD report that specialized services and supports are highly valued (Bhopti et al., 2020). This is understandable since higher severity of support needs and lower levels of adaptive skills have been found to negatively impact individual QoL (Balboni et al., 2020; Simões et al., 2016). Additionally, adequacy of public professional services and the quality of relationships with public service providers have been significantly linked to FQoL (Summers et al., 2007). However, school settings and educators are very rarely considered amongst these professional support services and service providers. Instead, studies tend to focus on medical personnel and therapeutic services. This is a critical oversight considering the significant role that schools play in the lives of children who attend them.

The supportive services that parents of children with DD value so highly are frequently less accessible within rural communities (Sibley & Weiner, 2011). However, adults living in urban areas tend to report lower life-satisfaction than those in smaller communities (Helliwell et al., 2019; Maier & Kim, 2008). This has not been specifically examined among families caring for children with DD. It is unclear whether the increased access to services in urban centres (such as those available within larger schools) may offset the low QoL reported in urban settings among families of children with DD. While it has been suggested that the implementation of

FQoL-based frameworks within the education system could be used to improve QoL for children with DD and their families, the relationships between CQoL, FQoL, and school factors have not actually been investigated thoroughly (Faragher & Van Ommen, 2017; Heras et al., 2021). The goal for this study was to close this gap.

Purpose

For our study, we were interested in how school factors related to CQoL and FQoL for children with severe DD. Specific variables we wanted to consider were type of classroom placement, specialized services offered within schools, and parental satisfaction with schools. Our goal was to determine whether these school factors were significant predictors of CQoL and FQoL. We anticipated that favourable perceptions of school factors would be positively correlated with CQoL and FQoL. Furthermore, we expected that school factors would predict CQoL and FQoL over and above variables throughout other levels of the environment.

Method

Design

Data for this study were collected as part of the team Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) project led by Dr. Adrienne Perry at York University and funded by the Canadian Institutes of Health Research. It included several different survey and in-person studies. The GO4KIDDS survey project was approved by the York University Office of Research Ethics in 2013. The current study utilized data from the survey project, taking a mixed methods approach whereby primary analyses were conducted using quantitative data and qualitative information was used as a supplement to fill in gaps. Quantitative data included several standardized measures and researcher-constructed measures

(described in Measures below). Additionally, parents provided brief written responses to an open-ended question about their children's school experiences.

Participants

Participants were 171 caregivers (93.0% female) ranging in age from 24 to 58 years ($M = 42.38$) of school-aged children with severe DD (see Table 1). The children were 68.8% male ($n = 117$) and ranged in age from 4 to 19 years ($M = 11.03$). Participants were recruited through websites and agencies providing services for children with DD, intellectual disability, and ASD. Of these children, roughly half had DD only and half also had a co-occurring ASD. All participants resided in Canada with the majority living in urban and suburban areas. The majority of the children attended public schools. Within schools, approximately 12% of children were placed in mainstream classrooms with minimal assistive services, 36% were in mainstream classrooms with one-to-one assistance, and 53% were in special education classrooms.

Table 1
Descriptive Statistics for Categorical Variables

| Child | <i>N</i> | % |
|--------------------------------------|----------|------|
| Sex | | |
| Male | 117 | 68.8 |
| Female | 53 | 31.2 |
| Diagnosis | | |
| DD only | 74 | 43.5 |
| DD and ASD | 96 | 56.5 |
| School | | |
| Public | 152 | 88.9 |
| Private | 14 | 8.2 |
| Other | 6 | 3.0 |
| Classroom Type | | |
| Regular class, no full-time support | 20 | 11.8 |
| Regular class, full-time 1:1 support | 60 | 35.5 |
| Special education class | 89 | 52.7 |
| Community Size | | |
| Urban | 74 | 43.5 |
| Suburban | 54 | 31.8 |
| Rural or remote | 42 | 24.7 |
| Parent/Family | | |
| Sex | | |
| Male | 12 | 7.0 |
| Female | 159 | 93.0 |
| Country of Birth | | |
| Canada | 130 | 76.0 |
| Other | 41 | 24.0 |
| Education | | |
| Less than high school | 6 | 3.6 |
| High school | 27 | 15.9 |
| Some college | 25 | 14.7 |
| College or university graduate | 86 | 50.6 |
| Graduate degree | 26 | 15.3 |
| First Language | | |
| English | 143 | 83.6 |
| Other | 28 | 16.4 |

Measures

CQoL

CQoL was measured using a 3-item parent-report scale from the GO4KIDDS survey (Perry & Weiss, 2008). Questions pertain to child happiness, achievement of potential, and quality of friendships (Ncube et al., 2018) and each is rated on a 5-point Likert scale. These ratings are summed to compute a continuous score with potential values ranging from 3 to 15. The established scale reliability reported by Ncube et al. (2018) for the composite CQoL score is acceptable for a scale of this length ($\alpha = .64$). Reliability in our sample was weaker ($\alpha = .42$) but the total score still had strong correlations with several of our other measured variables.

FQoL

FQoL was measured using the Beach Center FQoL Scale (Hoffman et al., 2006). This measure is divided into five subscales: family interaction, parenting, emotional wellbeing, physical and material well-being, and disability-related support. There are five items per subscale and each item is rated on a 5-point Likert scale based on satisfaction (very dissatisfied to very satisfied). Scores can be computed for individual subscales and for a total FQoL score. The measure had excellent internal consistency ($\alpha = .94$).

Child Severity

Adaptive and maladaptive behaviours were measured using the Scales of Independent Behaviour – Revised (Bruininks et al., 1996). Ratings for the 35 adaptive items (e.g., motor skills, communication, self-care) range from 0 (*never/rarely does*) to 3 (*does very well*). The adaptive scale had excellent internal consistency ($\alpha = 0.96$). The maladaptive behaviour scale consists of eight behaviours (e.g., aggression, inattention, noncooperation) which are rated based

on frequency and severity. Scores can range from the most severe behaviours (-72) to the average range (-10 to +10). This scale also had strong internal consistency ($\alpha = 0.92$).

Parent Mental Health

Mental health difficulties of parents were measured with the Kessler Psychological Distress Scale (K6; Kessler et al., 2003) which quantifies non-specific psychological distress. The six items are rated on a 5-point Likert scale whereby higher ratings indicate greater mental health problems. Questions examine feelings such as nervousness, hopelessness, and sadness. This measure is a good screening tool for mental health problems, and it had good internal consistency ($\alpha = .90$).

Parent Self-Efficacy

Parenting self-efficacy was measured using the Family subscale of the Family Empowerment Scale (Koren et al., 1992). This subscale has parents rate their agreement (on a 5-point Likert scale ranging from *not true at all* to *very true*) with 12 items regarding their parenting and family unit (e.g., “when problems arise with my child, I handle them very well” and “I feel my family life is under control”). Internal consistency was strong for this subscale ($\alpha = .90$).

Socioeconomic Status

Socioeconomic status was measured using a modified version of the Barratt Simplified Measure of Social Status (Barratt, 2005). Two raters assigned scores to the respondent's (i.e., caregiver) and respondent's partner's (if applicable) highest level of schooling completed (ranging from 3 to 21) and occupation (ranging from 5 to 45). Ratings were combined to compute a continuous total score. Inter-rater reliability was strong with a correlation of $r = .93$.

Social Support

Social support was measured using a modification of a brief scale from the GO4KIDDS Basic Survey (Perry & Weiss, 2008). The original scale has questions for various sources of support (family, friends, etc.). Items are rated on 5-point Likert scales ranging from -1 (*make it more difficult*) to 3 (*extremely helpful, I depend on them*). Ratings are summed to compute two subscale total scores (i.e., for family and community support). For the present study, we created two scores. We combined helpfulness scores for respondents' parents, parents-in-law, and extended family to create a measure of broader family social support and we combined helpfulness of work friends, friends from religious/cultural groups, neighbours, and other friends to create a measure of broader community social support.

School Services

Levels of support for school services were computed on a continuous 10-point scale. Parents were asked to identify whether their children received any of five specialized services through their schools: speech and language therapy, occupational therapy, physiotherapy, behaviour therapy, and problem behaviour support. Parents also indicated whether each service was a direct intervention or consultation only. Two points were allocated for each direct intervention service and one point was allocated for each consultation service. Points were summed to compute total scores ranging from 0 (no services received from schools) to 10 (direct interventions received across all five school services listed).

School Satisfaction

Parental satisfaction with schools was measured with the GO4KIDDS School Satisfaction Scale (Perry et al., 2019). The 9-item scale measures parent satisfaction with their child's type of classroom and education program, classroom staff, communication with school staff, specialized

treatments received in school, process of setting goals by the school, academic progress, behavioural progress, social skills progress, inclusion in class activities, and social inclusion by typical peers. Each item is rated on a Likert scale ranging from 1 (*very dissatisfied*) to 5 (*very satisfied*). The scale had high internal consistency reliability ($\alpha = .93$).

Demographic Information

Additional demographic information that was collected included child age, sex, and diagnosis, parent age and sex, type of classroom placement, and community size.

Qualitative Data

Parents were also invited to provide written responses. These were collected via an open-ended question (“please add any comments about your child’s school situation”) with the goal of better understanding any issues not addressed sufficiently by survey measures.

Statistical Analyses

Data were analysed using IBM SPSS Statistics V28 software (2021). Prior to conducting our primary data analyses, we performed preliminary analyses to examine data and screen for input errors, missing data, and impossible values. No input errors or impossible values were detected. Participants who were missing data for either of the dependent variables (FQoL and CQoL) were removed from the dataset ($n = 14$). Descriptive statistics and distributions were computed for all variables and skewness and kurtosis were examined (see Table 2). Most data were normally distributed but maladaptive behaviours were slightly negatively skewed and parent mental health and school services were slightly positively skewed. Internal consistency of the measures for this sample were evaluated using Cronbach’s alphas. These alphas were all considered to range from acceptable to excellent.

Table 2
Descriptive Statistics for Continuous Variables

| Measure | <i>M</i> | <i>SD</i> | Minimum | Maximum | Possible Range |
|--|----------|-----------|---------|---------|----------------|
| FQoL (raw mean) | 3.67 | .67 | 1.48 | 5.00 | 1 to 5 |
| CQoL (raw score) | 8.05 | 2.21 | 3.00 | 14.00 | 3 to 15 |
| Child Age (years) | 11.03 | 3.28 | 4.16 | 19.43 | - |
| Parent Age (years) | 42.37 | 6.98 | 24.95 | 57.91 | - |
| Adaptive Behaviour (standard score) | 55.00 | 20.67 | 3.00 | 99.00 | 0 to 105 |
| Maladaptive Behaviour (raw score) | -15.57 | 12.58 | -56.00 | 4.00 | -74 to 10 |
| Parent Mental Health (raw score) | 6.47 | 5.26 | .00 | 24.00 | 0 to 24 |
| Parent Self-Efficacy (raw mean) | 3.87 | .59 | 2.33 | 5.00 | 1 to 5 |
| Socioeconomic Status (raw score) | 38.63 | 14.58 | 8.00 | 66.00 | 8 to 66 |
| Family Support (raw score) | 1.99 | 2.09 | -3.00 | 7.00 | -3 to 7 |
| Community Support (raw score) | 1.94 | 1.90 | -4.00 | 10.00 | -4 to 10 |
| School Services (raw score) | 2.77 | 2.06 | .00 | 10.00 | 0 to 10 |
| School Satisfaction (raw mean) | 3.53 | 1.05 | 1.00 | 5.00 | 1 to 5 |

Correlational analyses were computed to determine the strengths of relationships between variables, informing decisions on which variables to retain for our regression analyses.

Categorical variables and variables that were insignificantly correlated with most or all other variables were examined further. This was done using two independent samples *t*-tests (for sex and diagnosis) and two one-way analysis of variance tests (ANOVA; for community size and classroom type) to compare differences in effects on CQoL and FQoL.

The primary quantitative data analyses consisted of two hierarchical multiple regressions. The first regression looked at predictors of CQoL. The first level of this regression considered child variables (age, diagnosis, adaptive behaviours, and maladaptive behaviours). The second level considered parent and family variables (parent self-efficacy, parent mental health, and family social support). The third level considered community variables (community social support and community size). The fourth level considered school variables (classroom type, school services and parental school satisfaction).

The second regression looked at predictors of FQoL. It was nearly identical to the first regression: the first level contained child variables (age, diagnosis, adaptive behaviours, and maladaptive behaviours), the second contained parent and family variables (parent self-efficacy, parent mental health, and family social support), the third contained community variables (community social support and community size), and the fourth contained school variables (classroom type, school services, and parental school satisfaction).

Qualitative Analyses

From our sample of 171 caregivers, 123 provided written responses to an open-ended question about their child's general school experiences. These written responses were analysed qualitatively to establish themes. This was done by utilizing a latent, theoretical thematic

analysis method (Braun & Clarke, 2006). Patterns of prevalent responses were analysed using a top-down approach to develop categories. As the primary coder, I familiarized myself with the data and compiled preliminary impressions, searched for themes, and developed operational definitions for themes. Two coders then assessed the responses separately and assigned them to thematic categories and identified emotional connotations in responses (positive, negative, or neutral). Inter-coder reliability was calculated using a method whereby agreement on the presence and absence of codes were considered (Mao, 2017). Inter-coder reliability was strong at 86%. Disagreement was accounted for in the results by calculating and reporting the average number of codes for each theme and connotation.

Results

Univariate Results

Correlations were calculated to examine the relationships of CQoL and FQoL with all other variables (see Table 3). Correlations of $|r| \geq .50$ were considered strong and correlations of $|r| \geq .30$ were considered moderate (Cohen, 1988). Both CQoL and FQoL had moderate correlations with child maladaptive behaviours, parent mental health, family social support, and school satisfaction. CQoL was also moderately correlated with parent self-efficacy while FQoL was strongly correlated with parent self-efficacy. This means that CQoL and FQoL were higher for individuals who reported fewer maladaptive behaviours and parent mental health difficulties and greater family social support, parent self-efficacy, and school satisfaction. Neither CQoL nor FQoL were significantly correlated with child sex, child age, child diagnosis, child adaptive behaviours, socioeconomic status, community social support, community size, classroom type, or school services. Additionally, CQoL and FQoL were moderately correlated with one another (which is unsurprising since the same caregivers provided the responses for each of these

measures). Based on the results of these tests, and subsequent analyses (described below) of the categorical variables (for which correlations are less meaningful), we chose to retain and omit certain variables for our final regression analyses.

Table 3*Correlation Matrix*

| Variable | FQoL | CQoL | Sex | Age | Dx | MAL | ADP | PMH | PSE | FSS | SES | COM | CSS | CRM | SRV |
|----------|-------|-------|-------|------|------|-------|------|-------|------|------|------|------|------|-----|-----|
| CQoL | .46* | - | | | | | | | | | | | | | |
| Sex | .07 | .13 | - | | | | | | | | | | | | |
| Age | -.09 | -.11 | .06 | - | | | | | | | | | | | |
| Dx | -.16 | -.28 | -.45* | -.18 | - | | | | | | | | | | |
| MAL | .41* | .41* | .11 | -.09 | -.23 | - | | | | | | | | | |
| ADP | .16 | .05 | -.06 | .19 | .06 | -.09 | - | | | | | | | | |
| PMH | -.47* | -.30* | -.11 | -.04 | .28 | -.44* | -.10 | - | | | | | | | |
| PSE | .61** | .30* | .09 | -.11 | -.11 | .26 | .05 | -.40* | - | | | | | | |
| FSS | .33* | .31* | .02 | -.16 | -.06 | .12 | .09 | -.18 | .24 | - | | | | | |
| SES | -.13 | -.01 | .08 | .07 | .03 | -.09 | .15 | .07 | -.14 | -.09 | - | | | | |
| COM | -.12 | -.02 | .01 | .04 | .07 | .01 | .10 | .07 | -.01 | -.01 | .12 | - | | | |
| CSS | .23 | .27 | -.11 | -.18 | -.05 | .16 | .11 | -.31* | .13 | .10 | .06 | -.06 | - | | |
| CRM | -.15 | -.10 | -.00 | .25 | .05 | -.05 | -.17 | .00 | -.12 | -.07 | -.01 | .15 | -.22 | - | |
| SRV | .22 | .21 | -.04 | -.16 | -.13 | .19 | -.22 | -.19 | .13 | .17 | -.12 | -.21 | .06 | .04 | - |
| SAT | .36* | .37* | .13 | -.08 | -.12 | .26 | .10 | -.28 | .14 | .17 | -.08 | .03 | .11 | .11 | .19 |

Note. Dx = Diagnosis; MAL = Maladaptive behaviour; ADP = Adaptive behaviour; PMH = Parent mental health; PSE = Parent self-efficacy; FSS = Family social support; SES = Socioeconomic status; COM = Community size; CSS = Community size; CRM = Community social support; SRV = School services; SAT = School satisfaction

*moderate correlation ($|r| \geq .30$) **strong correlation ($|r| \geq .50$).

QoL by Sex

Sex of child was uncorrelated with both dependent variables but was further examined using *t*-tests (with a significance level of $p < .05$). Although, on average, female children had slightly higher CQoL scores ($M = 8.47, SD = 2.39$) than male children ($M = 7.86, SD = 2.11$), this difference was not statistically significant, $t(168) = -1.67, p = .073$. Similarly, while families of female children had slightly higher FQoL scores ($M = 3.75, SD = 0.75$) than families of male children ($M = 3.64, SD = 0.63$), this difference was not statistically significant either, $t(168) = -0.96, p = .192$. Thus, it was decided to drop the sex variable from the regression analyses.

QoL by Diagnosis

We also further examined child diagnosis since it was not correlated with either dependent variable. On average, children with DD alone had higher CQoL scores ($M = 8.77, SD = 2.28$) than children with DD and ASD ($M = 7.53, SD = 1.97$). A *t*-test revealed that this difference was statistically significant, $t(168) = 3.79, p = .037$, with a medium effect size (Cohen's $d = .59$). However, while families of children with DD alone had slightly higher FQoL scores ($M = 3.80, SD = 0.66$) than families of children with DD and ASD ($M = 3.60, SD = 0.63$), this difference was not statistically significant, $t(168) = 2.06, p = .816$. We chose to retain diagnosis as a variable in our final regression analyses due to its relevance to CQoL and for comparison to previous research.

QoL by Community Size

Community size, a trichotomous variable, was uncorrelated with both dependent variables as well, but was further examined via one-way ANOVAs. For CQoL, this revealed that there was not a statistically significant difference between community sizes (i.e., urban, suburban, and rural/remote), $F(2, 167) = 0.06, p = .940$. For FQoL, a one-way ANOVA

comparing the three community sizes was significant, $F(2, 167) = 3.31, p = .039$. Pairwise comparisons revealed that only suburban ($M = 3.84, SD = 0.63$) and urban ($M = 3.53, SD = 0.66$) communities differed significantly ($p = .011, 95\% \text{ C.I.} = [0.07, 0.54]$). It was decided to retain this variable because of its relevance in the Bronfenbrenner model.

QoL by Classroom Placement

Classroom type, also a trichotomous variable, was also uncorrelated with the dependent variables. A one-way ANOVA comparing differences in CQoL based on classroom placement (i.e., regular class without full-time support, regular class with full-time 1:1 support, and special education class) was statistically significant $F(2, 166) = 3.21, p = .043$. Pairwise comparisons revealed that the only differences were between children enrolled in regular classes with full-time support ($M = 8.65, SD = 2.31$) and children enrolled in special education classes ($M = 7.75, SD = 2.03$), $p = .038, 95\% \text{ C.I.} = [0.01, 0.43]$. A one-way ANOVA comparing differences in FQoL based on classroom placement was not significant, $F(2, 166) = 2.48, p = .087$. It was decided to retain this variable because of its relevance in the Bronfenbrenner model and for comparison to previous research. For its use in the regression analyses, it was broken down further into two categories: regular class (with or without support) and specialized class.

Regression Results

Following primary data analyses, the child variables that were retained for the first step of the regression analyses were age, diagnosis, maladaptive behaviours, and adaptive behaviours (sex was dropped). The parent and family variables that were retained for the second step were parent self-efficacy, parent mental health, and family social support (socioeconomic status was dropped). No community variables were dropped, and variables for the third step were community social support and community size. Finally, despite the insignificance of classroom

type and school services in the preliminary data analyses, all school variables (classroom type, school services, and school satisfaction) were retained for the final step due to their relevance to our research interests.

CQoL

The first regression regarded predictors of CQoL (see Table 4). Model 1 (considering child variables only) was statistically significant and accounted for 23% of variance in CQoL, $F(4, 130) = 9.61, p < .001$. Model 2 (adding in parent and family variables) was also statistically significant and accounted for an additional 7% of variance, $F(3, 127) = 13.81, p < .01$. Model 3 (adding in community variables) was not statistically significant and only accounted for an additional 3% of variance, $F(2, 125) = 16.10, p = .11$. Finally, Model 4 (adding in school variables) was statistically significant and accounted for an additional 5% of variance, $F(3, 122) = 19.50, p < .05$. This supports our hypothesis that school variables are important predictors, of children's quality of life, even after accounting for other relevant variables.

In the final model, the significant predictors were maladaptive behaviours ($\beta = .240, p < .01$), diagnosis ($\beta = -.176, p < .05$), family social support ($\beta = .183, p < .05$), community social support ($\beta = .159, p < .05$), and school satisfaction ($\beta = .225, p < .01$). All significant variables in the final model (aside from diagnosis which was categorical) were positively correlated with CQoL, meaning that higher scores on these measures were associated with higher CQoL. In other words, CQoL was higher when they had lower maladaptive behaviour and a diagnosis of DD only (not ASD) but was unrelated to their age or their level of adaptive behaviour. CQoL was also higher when there was more social support from extended family and community sources, but was unrelated to community size, parent mental health difficulties or parenting self-efficacy. Finally, CQoL was higher when parents were more satisfied with the child's school, but

unrelated to specialized services received in school. The overall model accounted for 38% of variance in CQoL.

Table 4
Regression Predicting Child Quality of Life

| Model | | <i>B</i> | <i>SE B</i> | β | <i>t</i> | <i>R</i> ² | ΔR^2 |
|-------|--------------------------|----------|-------------|---------|----------|-----------------------|--------------|
| 1 | (Constant) | 11.014 | .930 | - | 11.846** | .228 | - |
| | Maladaptive behaviours | .061 | .014 | .348 | 4.354** | | |
| | Adaptive behaviours | .012 | .008 | .115 | 1.460 | | |
| | Age | -.097 | .054 | -.144 | -1.783 | | |
| | Diagnosis | -1.038 | .361 | -.234 | -2.878** | | |
| 2 | (Constant) | 8.224 | 1.623 | - | 5.067** | .298 | .070 |
| | Maladaptive behaviours | .051 | .015 | .290 | 3.408** | | |
| | Adaptive behaviours | .008 | .008 | .071 | .909 | | |
| | Age | -.060 | .054 | -.089 | -1.114 | | |
| | Diagnosis | -.897 | .356 | -.202 | -2.519* | | |
| | Parent mental health | -.009 | .038 | -.022 | -.240 | | |
| | Parent self-efficacy | .485 | .310 | .130 | 1.566 | | |
| | Family social support | .222 | .083 | .210 | 2.687* | | |
| 3 | (Constant) | 7.519 | 1.679 | - | 4.478** | .323 | .025 |
| | Maladaptive behaviours | .050 | .015 | .285 | 3.381** | | |
| | Adaptive behaviours | .005 | .008 | .050 | .641 | | |
| | Age | -.035 | .054 | -.052 | -.649 | | |
| | Diagnosis | -.890 | .353 | -.200 | -2.522* | | |
| | Parent mental health | .012 | .039 | .029 | .312 | | |
| | Parent self-efficacy | .499 | .307 | .134 | 1.626 | | |
| | Family social support | .222 | .082 | .210 | 2.709** | | |
| | Community size | -.018 | .204 | -.007 | -.088 | | |
| | Community social support | .197 | .092 | .170 | 2.133* | | |
| 4 | (Constant) | 4.976 | 1.836 | - | 2.711** | .375 | .052 |
| | Maladaptive behaviours | .042 | .015 | .240 | 2.879** | | |
| | Adaptive behaviours | .003 | .008 | .026 | .333 | | |
| | Age | -.004 | .056 | -.006 | -.070 | | |
| | Diagnosis | -.783 | .348 | -.176 | -2.256* | | |
| | Parent mental health | .027 | .039 | .065 | .701 | | |
| | Parent self-efficacy | .475 | .300 | .128 | 1.581 | | |
| | Family social support | .193 | .081 | .183 | 2.393* | | |
| | Community size | .034 | .208 | .013 | .165 | | |
| | Community social support | .184 | .092 | .159 | 2.007* | | |
| | Classroom type | .315 | .359 | .071 | .879 | | |
| | School services | .069 | .085 | .065 | .814 | | |
| | School satisfaction | .472 | .163 | .225 | 2.895** | | |

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

FQoL

The second regression followed the same steps regarding predictors of FQoL (see Table 5). Like the regression for CQoL, models 1, 2, and 4 were statistically significant. Model 1 (child variables) accounted for 22% of variance in FQoL, $F(4, 130) = 9.24, p < .001$. Model 2 (parent and family variables) accounted for an additional 29% of variance, $F(3, 127) = 34.30, p < .001$. Model 3 (community variables) only accounted for an additional 2% of variance, $F(2, 125) = 36.42, p = .13$. Model 4 (school variables) accounted for an additional 4% of variance, $F(3, 122) = 39.71, p < .05$. In the final model, the significant predictors were maladaptive behaviours ($\beta = .177, p < .05$), parent self-efficacy ($\beta = .442, p < .01$), family social support ($\beta = .129, p < .05$), and school satisfaction ($\beta = .184, p < .01$).

Similar to the child regression, all significant variables in the final model were positively correlated with FQoL, meaning that higher scores on these measures were associated with higher FQoL. This is to say, FQoL was higher when children had lower maladaptive behaviour but was unrelated to their age, diagnosis, or adaptive behaviour. FQoL was also higher when parents had higher self-efficacy and received more social support from extended family, but was unrelated to parent mental health difficulties, community-based social support, and community size. Lastly, FQoL was higher when parents were more satisfied with the child's school but was unrelated to the child's classroom placement or specialized services received in school. The overall model accounted for 56% of variance in FQoL.

Table 5
Regression Predicting Family Quality of Life

| Model | | <i>B</i> | <i>SE B</i> | β | <i>t</i> | <i>R</i> ² | ΔR^2 |
|-------|--------------------------|----------|-------------|---------|----------|-----------------------|--------------|
| 1 | (Constant) | 4.078 | .283 | - | 14.408** | .221 | - |
| | Maladaptive behaviours | .021 | .004 | .391 | 4.864** | | |
| | Adaptive behaviours | .007 | .003 | .223 | 2.811** | | |
| | Age | -.024 | .017 | -.117 | -1.442 | | |
| | Diagnosis | -.137 | .110 | -.101 | -1.239 | | |
| 2 | (Constant) | 1.825 | .410 | - | 4.445** | .511 | .290 |
| | Maladaptive behaviours | .011 | .004 | .207 | 2.913** | | |
| | Adaptive behaviours | .004 | .002 | .136 | 2.093* | | |
| | Age | -.007 | .014 | -.036 | -.543 | | |
| | Diagnosis | .029 | .090 | -.022 | -.322 | | |
| | Parent mental health | -.021 | .010 | -.162 | -2.146* | | |
| | Parent self-efficacy | .502 | .078 | .445 | 6.405** | | |
| | Family social support | .049 | .021 | .152 | 2.326* | | |
| 3 | (Constant) | 1.915 | .425 | - | 4.503** | .527 | .016 |
| | Maladaptive behaviours | .011 | .004 | .215 | 3.044** | | |
| | Adaptive behaviours | .005 | .002 | .142 | 2.178* | | |
| | Age | -.004 | .014 | -.021 | -.310 | | |
| | Diagnosis | -.020 | .089 | -.015 | -.220 | | |
| | Parent mental health | -.017 | .010 | -.135 | -1.738 | | |
| | Parent self-efficacy | .505 | .078 | .448 | 6.500** | | |
| | Family social support | .048 | .021 | .151 | 2.340* | | |
| | Community size | -.097 | .052 | -.117 | -1.874 | | |
| | Community social support | .018 | .023 | .050 | .755 | | |
| 4 | (Constant) | 1.276 | .466 | - | 2.741** | .562 | .036 |
| | Maladaptive behaviours | .009 | .004 | .177 | 2.541* | | |
| | Adaptive behaviours | .004 | .002 | .124 | 1.864 | | |
| | Age | .004 | .014 | .018 | .254 | | |
| | Diagnosis | .007 | .088 | .005 | .082 | | |
| | Parent mental health | -.013 | .010 | -.105 | -1.361 | | |
| | Parent self-efficacy | .499 | .076 | .442 | 6.551** | | |
| | Family social support | .041 | .020 | .129 | 2.015* | | |
| | Community size | -.083 | .053 | -.101 | -1.580 | | |
| | Community social support | .015 | .023 | .041 | .624 | | |
| | Classroom type | .078 | .091 | .058 | .853 | | |
| | School services | .019 | .022 | .057 | .861 | | |
| | School satisfaction | .117 | .041 | .184 | 2.831** | | |

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

Post-Hoc Results

The total school satisfaction score was a significant predictor of both CQoL and FQoL in the regressions, even after accounting for all other variables entered earlier. In the interest of better understanding what specific aspects of school satisfaction impact CQoL and FQoL, we conducted two post-hoc regression analyses. Both regressions contained the nine individual items that make up the GO4KIDDS School Satisfaction Scale. In the regression predicting CQoL (see Table 6), the variables that were statistically significant were communication with school staff ($\beta = -.322, p < .05$) and the child's academic progress ($\beta = .268, p < .05$).

Table 6
Satisfaction Items Predicting Child Quality of Life

| Model | | <i>B</i> | <i>SE B</i> | β | <i>t</i> |
|-------|---|----------|-------------|---------|----------|
| 1 | (Constant) | 5.624 | .571 | - | 9.852** |
| | Type of classroom and education program | -.061 | .191 | -.036 | -.320 |
| | Classroom staff | .169 | .230 | .093 | .734 |
| | Communication with school staff | -.554 | .221 | -.322 | -2.510* |
| | Specialized treatments in school | -.078 | .143 | -.052 | -.544 |
| | School goal-setting process | .211 | .213 | .130 | .989 |
| | Child's academic progress | .445 | .217 | .268 | 2.051* |
| | Child's behavioural progress | .206 | .218 | .114 | .946 |
| | Inclusion in class activities | .157 | .226 | .091 | .697 |
| | Social inclusion by peers | .253 | .167 | .158 | 1.513 |

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

In the regression predicting FQoL (see Table 7) the only statistically significant individual variable was the child's behavioural progress ($\beta = .303, p < .05$).

Table 7
Satisfaction Items Predicting Family Quality of Life

| Model | | <i>B</i> | <i>SE B</i> | β | <i>t</i> |
|-------|---|----------|-------------|---------|----------|
| 1 | (Constant) | 2.888 | .176 | - | 16.425** |
| | Type of classroom and education program | -.050 | .059 | -.096 | -.844 |
| | Classroom staff | .000 | .071 | -.001 | -.007 |
| | Communication with school staff | -.035 | .068 | -.067 | -.515 |
| | Specialized treatments in school | .083 | .044 | .184 | 1.880 |
| | School goal-setting process | -.001 | .066 | -.002 | -.013 |
| | Child's academic progress | -.040 | .067 | -.079 | -.594 |
| | Child's behavioural progress | .166 | .067 | .303 | 2.474* |
| | Inclusion in class activities | .043 | .069 | .082 | .619 |
| | Social inclusion by peers | .078 | .052 | .160 | 1.514 |

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

It should be noted that the results of these post-hoc regressions should be interpreted with caution since each variable is only representative of a single questionnaire item with a limited range of responses (1 to 5) and not necessarily normal distributions.

Qualitative Results

Using individual questionnaire items, or even a group of structured items in a scale, as predictors of QoL has limitations. For this reason, we chose to qualitatively analyse written comments about school experiences to broaden our understanding of the relationships between school factors and QoL for our participants. Themes were developed using an approach from Braun and Clarke (2006). All responses were analysed separately by two coders. Themes in responses were identified and also coded as positive, negative, or neutral. Seven themes were identified with an average of $N = 275.5$ total occurrences recorded (see Table 8). The most commonly occurring themes were *Everybody's Got a Story* and *Teaching Is Not About Power*

but There Is Great Power in Teaching. 28% of all themes had positive emotional connotations, 54% had negative connotations, and 18% were rated as neutral.

Table 8
Frequencies of Themes and Connotations

| Theme | <i>n</i> | % |
|--|----------|------|
| Everybody's got a story. | 52.5 | 19.1 |
| Positive | 15 | |
| Negative | 37 | |
| Neutral | 0.5 | |
| Teaching is not about power, but there is great power in teaching. | 50.5 | 18.3 |
| Positive | 21 | |
| Negative | 26 | |
| Neutral | 3.5 | |
| Bad systems beat good people. | 41 | 14.9 |
| Positive | 5 | |
| Negative | 33 | |
| Neutral | 3 | |
| Where am I supposed to be? | 40.5 | 14.7 |
| Positive | 9.5 | |
| Negative | 9.5 | |
| Neutral | 21.5 | |
| Change is inevitable. | 37.5 | 13.6 |
| Positive | 9.5 | |
| Negative | 13.5 | |
| Neutral | 14.5 | |
| Better together. | 29 | 10.5 |
| Positive | 9.5 | |
| Negative | 15 | |
| Neutral | 4.5 | |
| Is the sky really the limit? | 24.5 | 8.9 |
| Positive | 6.5 | |
| Negative | 15 | |
| Neutral | 3 | |

Themes

Everybody’s Got a Story. This theme consists of overall experiences and salient, specific personal experiences within the school system. The average number of occurrences of this theme was $n = 52.5$. Of these responses, 29% were positive (e.g., “our school has been exceptional, and it is a main reason why we have stayed in this community”), 70% were negative (e.g., “my child has 2:1 assistance at all times and escaped from school. He was found running down a busy street, and not by school staff. It is very stressful leaving him with other caregivers knowing the dangers”), and 1% were neutral (e.g., “he takes a bus to school, so I do not get to meet the other kids in his class or the other families”).

Teaching Is Not About Power, but There Is Great Power in Teaching. This theme is in relation to educational staff (including teachers, support staff, and administrative staff). The average number of occurrences of this theme was $n = 50.5$. Of these responses, 42% were positive (e.g., “classroom teacher and [educational assistant] are wonderful to work with and have built an amazing relationship with student and home”), 51% were negative (e.g., “totally inexperienced teacher, lazy, irresponsible. No passion in kids not to say kids with special needs. Can't even do an [individualized education plan] right. Refused to implement recommendations by [speech and language pathologist] saying it's too much”), and 7% were neutral (e.g., “the child's academic level directly depends on the teacher's ability to tolerate his disability and how well the teacher and school staff are educated about disability and different strategies to deal with him”).

Bad Systems Beat Good People. This theme is relating to the performance of the education system, in general. The average number of occurrences of this theme was $n = 41$. Of these responses, 12% were positive (e.g., “the school division has done very well for the limited

resources they are given”), 80% were negative (e.g., “school has been even more challenging than the disability itself. The [individualized education plan] process is a joke and the lack of knowledge on how to meaningfully educate a child with profound challenges is incredibly frustrating”), and 7% were neutral (e.g., “at this point in time we have taken the reins where our child's [individualized education plan] is concerned, we have now re-directed the team towards life skills and preparation for impending adulthood”).

Where Am I Supposed to Be? This theme encompasses the types of educational placements (classroom, school, educational support, etc.) that children experienced. The average number of occurrences of this theme identified by both coders was $n = 40.5$. Of these responses, 23% were positive (e.g., “my son is not ready for a regular classroom, so I am very, very grateful to have a specialized class to meet his needs”), 23% were negative (e.g., “although he is supposed to be integrated in a regular classroom, I have recently learned that he is spending most of his time in the learning centre, thus missing out on social connections with his own peer group”), and 53% were neutral (e.g., “he is in a regular classroom with one on one support”).

Change Is Inevitable. This theme is in reference to changes that occur over time as well as the unpredictability and instability that occurs as a result. The average number of occurrences of this theme was $n = 37.5$. Of these responses, 25% were positive (e.g., “the school situation has changed radically this fall - he has a teacher who has expectations and is willing to push him. The previous two years of schooling were entirely inadequate, but for the moment we are satisfied”), 36% were negative (e.g., “my daughter will be moving on to high school next year where I feel she will not get the same education and will just be ‘babysat’”), and 39% were neutral (e.g., “there is huge variation between years, teachers, and schools”).

Better Together. This theme is regarding inclusion and peer relationships. The average number of occurrences of this theme was $n = 29$. Of these responses, 33% were positive (e.g., “students are supported to include her and treat her kindly, and many people are able to look beyond the challenging behaviours and appreciate my daughter's gifts”), 52% were negative (e.g., “in the public they will promote inclusion, but that is not what happens out of the public's eye”), and 16% were neutral (e.g., “they tend to keep the special education kids separated from the rest of the kids”).

Is the Sky Really the Limit? This theme refers to what a child learns in school and the extent of their success in achieving goals set by their family and the school. The average number of occurrences of this theme was $n = 24.5$. Of these responses, 27% were positive (e.g., “she has already grown so much and tells us what she is learning which she never did before”), 61% were negative (e.g., “they are not educating our son. He is being babysat for his most vital learning hours”), and 12% were neutral (e.g., “the students work on both academic skills and social skills”).

Discussion

The purpose of this mixed-methods study was to better understand the associations between school factors and QoL for children with severe DD and their families. This was investigated through the analysis of standardized questionnaire measures completed by caregivers as well as written responses to an open-ended question about general school experiences. The design of our study was inspired by Bronfenbrenner’s Ecological Systems Theory (1979) wherein influences at different levels of the environment were accounted for in considering the wellbeing of children with severe DD. This was broken down into four main levels of influence: the child, the parents and family, the community, and the school system.

Integrating the Quantitative and Qualitative

The quantitative measure that we used (the GO4KIDDS School Satisfaction Scale; Perry et al., 2019) accounted for different aspects of school satisfaction, several of which overlapped with the qualitative themes we observed. *Teaching is not about power, but there is great power in teaching* supplements the information we have on parental satisfaction with the classroom staff and the parents' communication with school staff. *Is the sky really the limit?* captures some additional nuances in parental satisfaction with children's academic and behavioural progress. *Bad systems beat good people* provides supplementary information on the type of classroom and education programs that children attend, the school goal-setting processes, and the specialized treatments and services (or lack thereof) that children receive in school. *Better together* helps to provide a clearer understanding of parental satisfaction with the children's inclusion in class activities and their social inclusion by peers. *Change is inevitable* is a theme that spans all of the concepts captured by our quantitative measure as it recognizes differences in satisfaction can shift across experiences. Additionally, *Everybody's got a story* accounts for diverse but highly influential experiences that could not otherwise be captured by a survey measure. Taken together, this integration of information provides a thorough overview of the challenges and successes that children with severe DD and their families experience within the school system.

Child Factors

CQoL and FQoL were influenced by several concepts throughout all levels of the environment. The child-specific variables that we considered were adaptive and maladaptive behaviours, sex, age, and diagnosis. As has been found in previous research, increased challenging behaviours in our sample predicted lower QoL for both children and their families (Brown et al., 2006; Ncube et al., 2018). Interestingly, we did not find a similar relationship

between adaptive behaviours and QoL. This is contrary to previous research on adults with DD, which has found that higher levels of adaptive behaviours do predict increased individual QoL (Balboni et al., 2020; Simões et al., 2016), but consistent with findings from a study on children with ASD in which adaptive behaviour was not associated with QoL (Schneider et al., 2022). This could imply that the negative impact of maladaptive behaviours on both individual children and their families is amplified when considering wellbeing, but age-expected behaviours do not have a conversely positive impact.

CQoL was significantly predicted by diagnosis meaning that children with DD alone had higher CQoL than children with DD and ASD. A possible explanation for this finding could be that diagnosis was mildly associated with maladaptive behaviour. That is, children with both DD and ASD had slightly increased occurrences of maladaptive behaviours and, thus, lower CQoL. This is aligned with other research that has found that individuals with greater numbers of co-occurring conditions have more challenging behaviours and lower QoL (Leader et al., 2021). However, diagnosis did not influence FQoL, suggesting that there is no difference in QoL for parents of children with only DD and children with both DD and ASD.

In addition, we did not find any associations between QoL and child sex or age. While there is little precedence for an association between sex and QoL, some research has found that increased age may be associated with lower QoL (Ncube et al., 2018; Vos et al., 2010). Subjectively, we observed several written comments that indicated a drop-off of support services as children aged which could explain why other studies have found this association. However, our correlational analysis indicated that the relationship between age and support services was not significant for our sample. It is unclear why our findings regarding age are contrary to some other studies.

Parent and Family Factors

All family variables included in our regression analyses were moderately to strongly correlated with CQoL and FQoL, but not all of them were significant predictors. In other words, while all parent and family variables in our regressions were related to QoL, they did not necessarily predict it. However, socioeconomic status (which was not included in our regression analyses) was not significantly associated with either of our QoL measures. This is surprising since a lot of research indicates that lower socioeconomic status may predict lower QoL (Knorst et al., 2021). Notably, Canada has universal healthcare which could relieve a significant amount of burden associated with accessing disability-related support. This could make our sample fundamentally different from those studied in previous research on socioeconomic status.

Social support from extended family significantly predicted both CQoL and FQoL. While there is very little other research specifically on CQoL, this finding is aligned with several studies showing that social support is an impactful aspect of FQoL and QoL in adults (Cai et al., 2023; Hassanein et al., 2021; Lei & Kantor, 2022; Wang et al., 2022). Interestingly, even though parents provided responses on behalf of their children, parent mental health and parent self-efficacy did not predict CQoL. Although these parent variables presumably have strong influence on parents, themselves, they are not necessarily related to their children's lives, or at least so the parents believe. This finding provides support for our measure of CQoL as a unique and independent construct, even when rated by third-party respondents.

In fact, parent self-efficacy did significantly predict FQoL. The considerable contribution of both parent self-efficacy and social support has been mirrored in previous research wherein these two variables accounted for as much as half of the variance in FQoL (Feng et al., 2022). Additionally, parental coping skills, adaptability, and family cohesion (concepts partly captured

by measures of parent self-efficacy) also contribute to FQoL (Lei & Kantor, 2022; Wang et al., 2022).

Parent mental health was a significant predictor of FQoL in earlier steps of the regression analysis, but with the addition of all other variables it became insignificant. This indicates that, while parent mental health is important for FQoL, it is not as important as or overlaps with many of the other factors for which we accounted. While other research has found that parent mental health can significantly predict FQoL (Ncube et al., 2018), it is possible that the variables we considered better captured the concept than those used in other studies.

Community Factors

Although previous research has shown that community size can predict QoL (Helliwell et al., 2019; Maier & Kim, 2008), we did not find this. Notably, previous research has been limited to adults without DD, which could explain the difference in our findings. In line with previous findings (Bhopti et al., 2020; Sibley & Weiner, 2011), written comments from parents in our sample indicated that disability support services (which are presumably more readily available in larger communities) were highly desired. However, several comments also indicated that smaller communities felt supportive and like “family” and perhaps this tight-knit bond makes up for the lack of specialized services. Thus, communities of all sizes have benefits and deficits, resulting in community size being a poor predictor of QoL in our sample.

Social support from the broader community was a significant predictor of CQoL but not FQoL. This contrasts with a vast majority of research that has found that social support has great influence on FQoL (Cai et al., 2023; Hassanein et al., 2021; Lei & Kantor, 2022; Wang et al., 2022). Of note, other research generally combines social support from family members with that of support from friends, neighbours, and broader community members whereas we divided social

support into two categories (for family members and non-family members). Seeing as family social support was significant in our analyses and community social support was not, we may have captured a more nuanced picture of social support than previous research studies. It is likely that the significance attributed to social support in other studies also stems primarily from familial support. Additionally, we not only considered the presence / availability of social support but the perceived helpfulness of these sources. The significance of community social support for CQoL may be a result of the positive benefits a greater support system offers through additional opportunities for participation in recreation and leisure activities. However, it is unclear why this additional support is not predictive of FQoL. It may simply be that since the other variables in our model accounted for more variance in FQoL than community social support, this variable is comparably insignificant.

School Factors

In contrast to what we anticipated, classroom placement was unrelated to QoL for both children and their families. Previous studies have found that parents of children with severe DD tend to be more satisfied with specialized classes and schools (Bhopti et al., 2020; Perry et al., 2020) so it is somewhat surprising that placement did not impact QoL. Perhaps even more so since our sample is partially overlapping with that from Perry and colleagues' study (2020). However, they were specifically interested in factors that impacted school satisfaction whereas we were concerned with factors that impacted QoL. It may be that classroom placement indeed played a role in determining school satisfaction among our participants but that the degree of satisfaction with these placements (among other aspects of school) was what predicted QoL. Qualitative analyses may help to shed some light on this finding. Parents provided equal instances of positive and negative comments referring to educational placements with the

majority of these comments being neutral. Additionally, different parents reported both satisfaction and dissatisfaction with similar placements (e.g., “he is in a special education class where all the children have needs which is taxing on staff and other students” versus “the choice of segregated school with children similar to him has been just wonderful”). It is likely that it is not the placement itself that influences QoL but how effective the placement is in meeting the needs of the child and their family.

Similarly, school services did not have an impact on CQoL or FQoL. Although previous research has shown that positive relationships with public service providers can positively impact QoL (Summers et al., 2007), we did not find this to be the case in the context of the school system. It should be noted that we only accounted for a limited number of service providers and only those received through the school system (not other medical, social, or therapeutic services received elsewhere) so there could be others that are more impactful. On the surface, this finding seems to be in contrast to the several written comments we obtained mentioning the desire for more services such as applied behaviour analysis, occupational therapy, and speech and language pathology within schools. However, like our finding with classroom placement, it may be that it is not simply the presence of these services that is associated with QoL, but their efficacy and alignment with the needs of particular students. As such, it seems that the broader construct of educational satisfaction is the most important aspect of school for children with severe DD and their families.

Indeed, we found that school satisfaction significantly predicted both CQoL and FQoL, over and above all other variables. As a concept that has never been directly studied, this finding highlights an immensely influential aspect of life for these children and their families. This concept of satisfaction (or lack thereof) can be seen within every qualitative theme we identified.

It seems that both positive and negative experiences within the school system are salient and incredibly impactful for these families. Consistent with previous literature, schools seem to have the ability to influence several aspects of life for individuals with DD (Bhopti et al., 2020; Carrington et al., 2016; Kurth et al., 2020; Ncube et al., 2018; Perry et al., 2020; Ruijs & Peetsma, 2009; Simón et al., 2022; Webster & Carter, 2013). With the right training, resources, and support, educational personnel have the capacity to facilitate wonderful experiences, potentially influencing overall QoL, for these children and their families.

Limitations and Future Directions

There are some limitations to the present research study that should be considered when interpreting the results. Firstly, we utilized caregivers as third-party respondents for children with severe DD since our sample participants were generally unable to complete self-report measures. Although previous research has found that self-report and third-party report measures of QoL are highly consistent (Simões et al., 2016), we recognize that parents may not have a perfectly accurate picture of how their children feel. Further, our measure of CQoL is limited in its scope and reliability since it is only made up of three items. Nevertheless, we feel that it is important to include this often-neglected population in research. Future research may seek to explore other ways to include individuals with severe DD.

Because the data for this study were collected in 2012 for a previous project, there are some constraints. It is possible that parental perceptions of school and disability have shifted over the past years. Specifically, the COVID-19 pandemic was a major life event that our respondents had not yet experienced. We recognize that the pandemic has put significant additional stressors on the education system and those interacting with it and our findings may not apply to this dynamic situation. Indeed, research on school closures and virtual schooling in relation to children with DD

(and their caregivers) has shown that there have been increased challenges with communication, accessibility, learning, stress, and mental health problems (Lipkin & Crepeau-Hobson, 2023; Sakız, 2022). However, as the world continues to recover from the effects of the pandemic, our findings will continue to be more relevant. Nonetheless, it could be beneficial to replicate our study at present to account for these temporal changes.

Additionally, since our data were collected for a previous project with different objectives, our measures were not selected with the present study in mind. Other measures may have better captured the concepts we were interested in, and future research may consider using other measures to replicate our study.

A final limitation of our study is the homogeneity of our sample. The majority of our respondents were well-educated mothers of male children with DD. Most families lived in urban areas and children largely attended public schools. As such, these sample characteristics should be acknowledged when considering the generalizability of our findings. Future research should seek to include individuals from even more diverse backgrounds. However, it is worth noting that our study consisted of a fully Canadian sample with representation across all provinces, which is quite rare in this field of research. This may also raise challenges since school systems, government funding allocation, and educational philosophies can vary across provinces. Continued research with widely representative Canadian samples may help to provide additional insight into these issues.

Conclusions

Our study has confirmed the significance of several influential factors of QoL for children with severe DD and their families as well as revealed some previously unidentified predictors. To the best of our knowledge, the concept of school factors in relation to QoL has

never been directly studied. We found that school satisfaction predicted QoL for both children and their families, over and above all other variables accounted for. Other influential factors of CQoL were child maladaptive behaviours, child diagnosis, family social support, and community social support. Predictors of FQoL also included child maladaptive behaviours and family social support as well as parent self-efficacy. Yet, as hypothesized, school factors accounted for additional unique variance beyond these other variables.

Classroom placement and school services were not significantly associated with QoL. This indicates that it is not simply the type of placement nor the provision of specialized services that predicts QoL but rather whether parents perceive these factors as being efficacious to their children. This newly acquired understanding of how the education system has the potential to influence QoL has significant implications for students, families, educators, and schools. The education system has a responsibility to provide inclusive treatment and effective teaching to all children. Based on the vast quantity of negative perceptions we acquired from our participants, schools have many areas upon which they can improve. Our findings may be used to guide educational training, practices, and policies to support positive experiences for students with DD and their families, of particular importance since these experiences are associated with overall QoL.

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