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Parental Perspectives on Supports and Services for Children with Emotional/Behavioural Disorders

by

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Without any doubt, this work is dedicated to the many children who inspire and challenge me day after day with their love, laughter, and courage.

- R.E.

ABSTRACT

In this qualitative study, parental perspectives were sought about the overall experiences of seeking support for children with Emotional/Behavioural Disorders (E/BD), from the early signs of disordered behaviour through the processes of diagnosis, assessment, and treatment. The parents of 4 children with Severe E/BD participated in interviews exploring child and family history, previous access to supports and services, and the perceived need for additional services for the child and/or family. Results were examined using multiple case study design, and indicated that parenting a child with E/BD results in significant impact on parental stress, employment, and health. The processes of assessment and diagnosis were perceived as confusing and overwhelming, and relationships with school personnel were often strained. The participants had variable experiences accessing supports outside of school. Examination of these perspectives suggests that continuity, collaboration, and communication continue to be necessary building blocks for developing effective child and family supports.

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- R.E.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1: INTRODUCTION

Educators, parents, and other service providers are called upon to continually collaborate with one another to meet the needs of children with Emotional/Behavioural Disorders (E/BD). As the course of development of E/BD is unique to the individual child, these relationships and the range of services required can be extremely complex. While a child may be at increased risk because of individual characteristics or factors in his or her environment, there is evidence that some of this risk can be mitigated by successful supports and interventions that serve to build resiliency.

From the parental perspective, the task of raising a child with E/BD can be overwhelming, and contribute to parental stress. As such, the need for supports for both the child and family is apparent. However, it is unclear how often or at what stages potential supports are available in schools and communities. Furthermore, where there are services available, there is limited information about how awareness of these services is raised with parents and advocates, how children and families gain access to them, or if parents understand the roles of different service providers.

Pugach (2001) makes a case for encouraging researchers in special education to take a broader view of qualitative research, in which the goal is to examine contexts in special education and to provide a voice for those whose voices have not yet been heard. This study strives to achieve this goal by viewing special education in the context and perspectives of the family, and providing a voice for parents of children with E/BD, whose viewpoints are seldom represented in current research.

Through qualitative interviews and a review of Student Records at each child’s school, information was collected regarding child and family history, previous access to supports and services, and the perceived need for additional services for the child and/or family. Perspectives were sought about the overall experiences of parenting and seeking support, from the early signs of disordered behaviour through the processes of diagnosis, assessment, and treatment, in order to draw conclusions about the services these children and families require, and how access to these services might be improved. Through multiple case study design, this information brings focus to parental experiences and views surrounding supports provided by community organizations, health care providers, and schools. The intent of this study was to develop an understanding of both common and unique experiences in parenting children with E/BD. In the analysis of results, individual differences as well as common themes that emerge are explored, with an emphasis on the successes and challenges faced by the participants as they sought support for their children and themselves.

It is hoped that exploring the parental perspective will serve to inform educators and service-providers as they seek to create collaborative environments and effective support systems for children with E/BD and their families. To this end, discussion focuses on the essential elements of continuity, collaboration, and communication in defining effective support.

CHAPTER 2: PERSPECTIVES ON EMOTIONAL/BEHAVIOURAL DISORDERS IN THEORY AND PRACTICE

Examining the perspectives of parents whose children have been diagnosed with Emotional or Behavioural Disorders (E/BD) is an important step towards creating successful placements and services, in which parents are involved and feel supported. In order to examine these perspectives, it is essential to begin with a shared definition of E/BD and a common perspective or theoretical framework. It is also necessary to briefly explore the research on related topics including the frequent use of placements other than the regular classroom, the stress and perceived lack of support affecting parents of children with E/BD, and the importance of parental involvement in special education.

Definitions and Classifications

Forness and Kavale (2000) put forward a strong proposal for using the following definition of E/BD in education:

> The term “emotional or behavioural disorder” means a disability that is characterized by behavioural or emotional responses in school programs so different from appropriate age, cultural, or ethnic norms that the responses adversely affect educational performance, including academic, social, vocational, or personal skills; more than a temporary, expected response to stressful events in the environment; consistently exhibited in two different settings, at least one of which is school-related; and unresponsive to direct intervention applied in general education, or the condition of a child is such that general education interventions would be insufficient. (p. 266)

Forness and Kavale (2000) note several reasons to support this definition, including the indication that an E/BD is more than a temporary response and can co-exist with other conditions, the inclusion of ethnic or cultural considerations, and the requirement that eligibility be based on data in more than one setting.

The Alberta Education Definition

Alberta Education has adopted its own definitions of E/BD in order to facilitate programming and funding decisions. The definition for the category referred to as Mild/Moderate Emotional/Behavioural Disability in Grades 1-12 (Code 53) is stated:

> A student identified with a mild to moderate emotional/behavioural disability exhibits chronic and pervasive behaviours that interfere with the learning and safety of the student/child, other students/children and staff.
>
> Typically, behaviour disabilities are characterized by a number of observable maladaptive behaviours:
>
> a) an inability to establish or maintain satisfactory relationships with peers or adults
>
> b) a general mood of unhappiness or depression
>
> c) inappropriate behaviour or feelings under ordinary conditions
>
> d) continued difficulty in coping with the learning situation in spite of remedial intervention
>
> e) physical symptoms or fears associated with personal or school problems
>
> f) difficulties in accepting the realities of personal responsibility and accountability

> g) physical violence toward other persons and/or physical destructiveness toward the environment.

In comparison, the definition for the category referred to as Severe Emotional/Behavioural Disability (Code 42) reads as follows:

> A student/child with a severe emotional/behavioural disorder is one who:
>
> - displays chronic, extreme and pervasive behaviours and requires close and constant adult supervision, high levels of structure, and other intensive support services in order to function in an educational setting. The behaviours significantly interfere with both the learning and safety of the student/ECS child and other students/ECS children. For example, the student/child could be dangerously aggressive and destructive (to self and/or others), violent and/or extremely compulsive; and
> - (for grades 1–12 students) has a diagnosis including conduct disorder, schizophrenia or bi-polar disorder, obsessive/compulsive disorders, or severe chronic clinical depression; and may display self-stimulation or self-injurious behaviour. In the most extreme and pervasive instances, severe oppositional defiant disorder may qualify.

The Government of Alberta makes statistics about the number of students who qualify for special education codes accessible to the public online (http://education.alberta.ca/admin/special/stats/bycode.aspx). In the 2007-2008 school year, 549,434 students under the age of 20 were registered in Alberta schools from Grades 1 to 12. Of these, 8,273 students were identified as having Severe Emotional/Behavioural Disabilities using the Alberta Education definition criteria. This represents about 1.5% of the population, or 1 in every 66 students. An additional 4,579 students were identified as having an Emotional/Behavioural Disability at the Mild/ Moderate level. When taken together, these students then represent 2.3% of the student population, or about 1 in every 43 students. Furthermore, students displaying significant emotional or behavioural difficulties might also be represented in other categories, such as Severe Multiple Disability (1,034 students), Mild to Moderate Multiple Disability (1,846 students), Severe Physical or Medical Disability (7,375 students), or Mild to Moderate Physical/Medical Disability (2,336 students). Without a doubt, students with significant emotional and behavioural difficulties constitute a substantial portion of the student population, with conceivably an enormous impact on education and service delivery.

The Developmental Perspective as a Theoretical Framework for Understanding E/BD

In order to contribute to theory, Merriam (1998) advises that in the study design, the researcher makes explicit the theoretical framework within which the study will be completed. The theoretical framework is the stance from which the researcher works, and the lens with which the world is viewed. To some extent, the theoretical framework also dictates which literature base will be used to define the concepts, problems, theories, and purposes of the study. While the framework for this study incorporates a range of perspectives, the most prevalent theoretical base on which it has been built stems from a developmental perspective.

Developmental perspectives seek to understand how people grow and change in relation to their environment (Wicks-Nelson & Israel, 2003). From this perspective, more than just the origins of behaviour are explored; adaptations (or, in the case of disordered behaviour, maladaptations) to the environment are equally important. Developmental perspectives rest on the shared assumption that there is a common and logical course of development that is expected, although it may be expressed in different ways. Disordered behaviour therefore emerges over time, and is understood in terms of deviation from normal development across the lifespan, or failure to negotiate developmental stages (Price & Lento, 2001).

The developmental perspective recognizes that the factors affecting disordered behaviour interact with one another in complex ways, such that the causes may be direct or indirect, and may play different or unequal roles (Wicks-Nelson & Israel, 2003). Moreover, any one factor or combination of factors may or may not be necessary or sufficient for the development of disordered behaviour (Tremblay, 2003). Developmental theory seeks to understand the processes or pathways by which causes work together to result in normal or deviant behaviour. Important distinctions are made between the concepts of equifinality, when pathways with different origins result in similar outcomes, and multifinality, when pathways with similar origins result in differing outcomes (Wicks-Nelson & Israel, 2003; Price & Lento, 2001). Understanding the processes which result in equifinality or multifinality is essential to the developmental perspective, and can be understood in terms of risk and protective factors that contribute to or ameliorate the development of disordered behaviours.

Both the individual and the environment are essential considerations in the developmental perspective, and their relationship to disorder can be defined in terms of genotype-environment correlations. These correlations may be passive (when the same factors indirectly affect both the child and the environment), evocative (when the child's characteristics elicit the environmental factors), or active (when the child's characteristics lead him or her to seek out specific environments) (Lahey & Waldman, 2003). The individual is understood to both shape the environment and react to it through complex and sometimes cyclical interactions (Price & Lento, 2001).

The developmental perspective is not exclusive, but allows room for the incorporation of many other perspectives or disciplines in terms of how they impact an individual over the lifespan. Other important aspects of developmental perspectives include the expectation of both change and continuity of behaviours, and the importance of early experience in determining later development (Wicks-Nelson & Israel, 2003). Using the lens of a developmental perspective clearly has direct implications for defining and understanding the progression of disordered behaviour.

The term 'behaviour disorder', as a categorical construct, has typically been used to refer specifically to Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD). This is in part a result of the classifications used in the Fourth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), in which ODD and CD are grouped with Attention Deficit Hyperactivity Disorder (ADHD) under the heading 'Attention-Deficit and Disruptive Behavior Disorders'. In developmental contexts, disruptive behaviour and aggression are understood as dimensional constructs that are applicable to a much broader range of disorders. As Blader and Jensen (2007) note, "many psychiatric conditions have aggressive behavior as a major complication" (p. 467). Disorders other than ODD or CD that commonly involve or co-occur with aspects of disordered behaviour include, but are not limited to: substance abuse, anxiety disorders, mood disorders, tic disorders, major developmental disorders, and cognitive or sensory disorders (Rey, Walter, & Soutullo, 2007; Blader & Jensen, 2007). As such, the risk or resilience factors and defining features of disordered behaviour may be applicable to its presence and development in any of these or other disorders. It is important to note that in the definitions used for a Severe E/BD education code in Alberta, several disorders other than ODD and CD are also included.

Risk and Resiliency

The concepts of risk and resiliency are central to developmental perspectives. Risk factors in the development of aggression are 'variables that increase the chance of behavioral difficulties or impairments' (Wicks-Nelson & Israel, 2003, p. 27). In contrast, resilience or protective factors are variables that increase the chance of positive adaptation or outcomes despite the presence of risk (Wicks-Nelson & Israel, 2003; Luthar & Prince, 2007). Neither risk nor resilience implies set pathways or causalities, but instead are factors that are likely to increase or decrease the probability of developing disordered behaviour.

There is no one necessary or sufficient risk or protective factor that ultimately determines disorder, but rather, the interplay between risk and resilience is dynamic and multifaceted, interacting in different ways for different individuals. Complexities such as the timing and specific circumstances surrounding a particular risk can influence how it impacts the individual. Furthermore, risk is widely considered to be cumulative (Wicks-Nelson & Israel, 2003; Rey, Walter, & Soutullo, 2007; Luthar & Prince, 2007; Pettit, Polaha, & Mize, 2001; Tremblay, 2003). That is, when risks coexist, "effects tend to be synergistic, with children's outcomes being far poorer than when any of these risks existed in isolation" (Luthar & Prince, 2007, p. 292).

Development involves both an individual and an environment that are continually changing. Risk and protective factors for the development of disordered behaviours can therefore be broadly categorized into those that are characteristic of the individual, and those that are attributable to the environment, with the recognition that it is not the isolation but the interaction of these factors that plays out in the development of pathways of behaviour.

Individual Factors

There are many factors inherent to the individual that may increase or decrease risk or resilience for behaviour disorders. This group of factors characteristic of the individual are also referred to as antisocial propensity (Lahey & Waldman, 2003). While not in any sense an exhaustive list, some of the most commonly recognized factors influencing antisocial propensity include: genetic and biological factors; cognitive abilities; temperament and personality; and social information processing.

Genetic and biological factors.

Disordered behaviours have been shown to be considerably heritable, with estimates of heritability of antisocial behaviour as high as 50% (Wicks-Nelson & Israel, 2003). In addition, life-course persistent patterns of aggression appear to be more heritable than adolescence-limited patterns (Luthar & Prince, 2007). This indicates that genetics play some role in the development of aggressive behaviour, although the mechanisms of its impact are not yet entirely clear. It is possible that genetics indirectly impact aggression by influencing aspects of social-cognitive functioning, including temperament, cognitive abilities, and processing skills (Luthar & Prince, 2007; Lahey & Waldman, 2003).

Biological predispositions for disordered behaviour can also include altered brain structure, nervous system maldevelopment, or neuroendocrine abnormalities, which are sometimes the result of prenatal complications or birth difficulties (Luthar & Prince, 2007; Moffitt, 2003; Tremblay, 2003). In particular, low levels of serotonin (Tremblay, 2003) and high levels of the stress hormone cortisol (Luthar & Prince, 2007) have been implicated in impulsivity and aggression.

A further biological factor influencing the development of behaviour is gender. Overall, fewer females than males display disordered behaviour, and when they do, females are less likely to display direct aggression. Some have suggested that one possible explanation for this gender variation is that females are exposed to fewer of the other associated risk factors (Moffitt, 2003).

Cognitive abilities.

Low intelligence and school achievement have been shown to predict aggressive behaviour (Farrington & Welsh, 2004). Like many other risk factors, the impact of intelligence may be indirect, either because lower cognitive ability increases frustration (Marcus, 2007, Chap. 2), or because it impedes the development of executive functioning skills, including problem solving and action regulation (Tremblay, 2003).

Temperament and personality.

Temperament and personality in children generally encompasses the factors of emotionality, behavioural inhibition, and sociability (Wicks-Nelson & Israel, 2003; Lahey & Waldman, 2003; Marcus, 2007, Chap. 3). Although these same constructs are sometimes defined using other terms, their basic meaning in relation to disordered behaviour remains relatively constant.

Emotionality in children with disruptive behaviour is often displayed as negative affect. Negative affect, characterized by intense anger, frustration, and irritability, combined with low emotional regulation, is an important predictor of disordered behaviour (Wicks-Nelson & Israel, 2003; Marcus, 2007, Chap. 3; Moffitt, 2003). Children prone to aggression also almost always have some element of impulsivity, or behavioural disinhibition. Impulsivity and the inability to regulate behaviour have been cited as the most important dimension of temperament in terms of the predictability of aggression (Farrington & Welsh, 2004). Elsewhere, the same construct of disinhibited behaviour has been identified as daring or sensation seeking personality traits (Lahey & Waldman, 2003), with similar predictive value. Finally, the temperament of children at risk for disordered behaviour includes some aspect of low sociability, or low display of prosocial behaviours (Marcus, 2007, Chap. 3; Lahey & Waldman, 2003). Whereas prosocial behaviours include sympathy, empathy, agreeableness, and conscientiousness, antisocial behaviours are characterized by a lack of these traits.

Social information processing.

Social information processing, or social cognitive processing, is the means by which individuals view social information, interpret it, and make decisions about how to respond (Wicks-Nelson & Israel, 2003; Pettit, Polaha, & Mize, 2001; Dodge, 2003). Social information processing serves as a mediator between experience and later behaviour, and therefore can provide clues about how disordered behaviour develops as a result of experience. As Pettit, Polaha, and Mize (2001) suggest, children with aggressive behaviours may be “deficient in their use of social cues” (p. 301) such that they interpret others' actions as hostile, attend more readily to aggressive cues, or follow more negatively patterned schema for interpreting and responding to others' behaviour.

Environmental Factors

Environmental risk and protective factors are sometimes characterized as either distal variables, which are considered background or distant from the individual, or proximal variables, which are present in a person's immediate context (Wicks-Nelson & Israel, 2003; Tremblay, 2003). These environmental variables may include parenting, community, and situational factors, among others.

Parenting and familial factors.

The strong impact of parenting on disordered or aggressive behaviour begins in infancy, with the formation of attachment. Poor attachment or weak relational bonds with parents are linked to antisocial behaviour and the development of difficult temperament (Wicks-Nelson & Israel, 2003; Luthar & Prince, 2007). Once behavioural difficulties begin to appear, parent-child interactions may take on a cyclical nature, with difficult behaviours eliciting coercive, harsh, or inconsistent parental responses, which in turn contribute to the child's expression of difficult behaviours (Blader & Jensen, 2007; Keisner, Dishion, & Poulin, 2001).

Maltreatment in the form of trauma, abuse, or neglect has also been shown to amplify risk for psychopathology by increasing antisocial behaviour (Blader & Jensen, 2007; Farrington & Welsh, 2004). Other family risk factors for the development of disordered behaviour include low parental supervision, high parental stress, parental conflict, disrupted families, and parental psychopathology, substance abuse, or antisocial behaviour (Blader & Jensen, 2007; Farrington & Welsh, 2004).

Of particular significance to the present study is the fact that the effects of risk may also be mediated through familial factors that serve to protect the child against the development of psychopathology, which are essentially the opposite of parental risk factors. Resiliency can be increased through supportive and responsive parenting, which involves developing strong family relationships, warmth, appropriate control, effective discipline, and monitoring (Luthar & Prince, 2007).

Community factors.

The communities in which children live also impact the development of disordered behaviour, albeit through more indirect means. Communities with lower socioeconomic standing contribute to increased risk for disruptive behaviour. This may relate in part to lower adult supervision in these communities, or to the tendency for adults with mental health issues of their own to reside in communities of lower socioeconomic status (Blader & Jensen, 2007; Farrington & Welsh, 2004). Another community factor hypothesized to impact aggression in particular involves modeling, whether through peer aggression, exposure to community violence, or to violence in the media (Blader & Jensen, 2007). Peer delinquency has been found to be an important predictor of delinquent behaviour, through the processes of reinforcement and status attainment. Similarly, peer rejection can increase risk of disordered behaviours (Blader & Jensen, 2007).

Protective functions that counter these community risk-factors can include access to mentors or support networks, religious affiliations, and supportive relationships with teachers (Luthar & Prince, 2007).

Situational factors.

Marcus (2007, Chap. 4), in reviewing the General Aggression Model, identified 6 situational or proximal factors that may directly heighten the risk for disordered behaviour in a given context. These factors are: provocation; frustration; pain and discomfort; drugs and alcohol; incentive; and aggressive cues. With the understanding that individual and situational characteristics interact to lead to aggressive or disordered behaviours, each of these proximal factors has been shown to increase the likelihood that inappropriate behaviour will be displayed in a given circumstance.

Comorbidities

Aside from individual and environmental factors, comorbidities also contribute to our understanding of risk and resiliency in disordered behaviour. The typically defined behaviour disorders of ODD and CD are most frequently diagnosed comorbidly with ADHD, mood disorders, and substance abuse (Rey, Walter, & Soutullo, 2007), with ADHD being the most prevalent (Blader & Jensen, 2007). When ODD and ADHD are diagnosed comorbidly, disordered behaviour is much more frequent and persistent than with ODD alone (Lahey & Waldman, 2003). Additionally, ADHD and ODD comorbid youth progress to features of CD earlier (Blader & Jensen, 2007).

Children with behaviour difficulties are also at greater risk for later substance use and abuse. One explanation for this comorbidity is that the risk and protective factors for substance abuse are developmentally similar to those for behaviour disorders, so much so that substance abuse is sometimes viewed as a subset of an individual's greater deviant or problem behaviours (Chassin & Ritter, 2001).

Additionally, as noted earlier, behaviour difficulties are frequently comorbid with cognitive difficulties, which may take on many forms including language deficiencies, learning disabilities, low intelligence, or other disorders that have the potential to co-occur with disordered behaviour by inhibiting social learning or increasing frustration.

Implications for Treatment and Prevention

Current understandings about the developmental progression of disruptive or aggressive behaviour, the risk and protective factors that influence this development, and the comorbid conditions frequently diagnosed with E/BD have many implications for treatment and prevention. In general, a developmental perspective would inform early, context-based, individual-specific treatment and intervention that addresses the range of difficulties the individual is experiencing. Prevention or treatment may be addressed using "a variety of psychological, behavioural, or pharmacological approaches, alone or in combination, targeting the child and/or the family" (Rey, Walter, & Soutullo, 2007, p. 461). Despite the fact that there are few consistently effective treatments with substantial research backing, certain types of treatment have had greater success than others (Rey, Walter, & Soutullo, 2007).

Because the most persistent forms of disordered behaviour begin early in life, interventions that are likely to be most effective also begin in early childhood (Farrington & Welsh, 2004; Tremblay & Nagin, 2005). Following from this, because of the strong influence family plays in early development, family-based approaches have seen considerable success in prevention and treatment of aggressive behaviour (Farrington & Welsh, 2004; Chassin & Ritter, 2001). Family interventions that support positive and effective parenting are likely to remain critically important, since so many of the risk and resilience factors for disordered behaviour stem from this domain (Keisner, Dishion, & Poulin, 2001).

Furthermore, comorbidities imply that multimodal treatment that addresses difficulties across functional domains is necessary. That is, effective treatment should be aimed not at one specific difficulty, but should take into account the range of difficulties likely experienced by the child. Direct social skills training programs that help children develop behavioural or emotional control and coping strategies have had some documented effectiveness (Rey, Walter, & Soutullo, 2007), as have some medication-based treatments (Blader & Jensen, 2007).

Developmental psychopathology has contributed much to the understanding of E/BD, including broadened definitions, constructs from which to understand pathways of disordered behaviour, and knowledge about risk and protective factors, which inform intervention and treatment. From this developmental perspective, E/BD is complex, and occurs differently in each child based upon a range of factors that interact to increase or decrease risk and resiliency (Wicks-Nelson & Israel, 2003). Certainly, there are factors outside of the child him/herself which may impact the development and management of an E/BD, and it can reasonably be concluded that effective supports and interventions are crucial to building resiliency. While there is still much to be learned and clarified about disruptive and aggressive behaviour, developmental perspectives give us both a place from which to begin deeper research into effective prevention, treatment and support, and a hope for future positive outcomes.

Related Areas of Research

Segregated and Special Education Programs

While inclusive and special education programming may both be used to address the needs of students requiring additional academic or behavioural accommodations, considerable support remains for the use of segregated programming within special education classrooms for students with E/BD.

Leyser and Kirk (2004), in a survey of parent views of inclusion, found that parents of students with disabilities expressed several concerns regarding inclusion. These concerns were related to the emotional development of the child, the quality of instruction, the potential loss of needed services, and the instructional skills and available time of the general classroom teacher. Furthermore, results revealed several variables related to parent perceptions about inclusion, most notably that parents of students with moderate and severe disabilities were less likely to support inclusion than parents of students with mild disabilities (Leyser & Kirk, 2004). The study also noted that students with moderate or severe disabilities are more likely to be served through separate classes (Leyser & Kirk, 2004).

Farmer, Quinn, Hussey, and Holahan (2001) identified the contributions of multiple factors in a systems view of behaviour development, similar to the developmental perspective. These factors include peer relations, parental factors, academic problems, attention problems and hyperactivity, and the onset, persistence, and recency of problem behaviour. Farmer et al. (2001) suggest that the self-contained classroom, with lower student-teacher ratios, may play a vital role in reorganizing this system of correlated risks for students at high-risk for the development of E/BD.

Kauffman, Bantz, and McCullough (2002) conducted a case study of a special education classroom for students with E/BD, noting the success of the program in increasing prosocial behaviour and academic improvement. Kauffman et al. (2002) assert that the case presented “bolsters the argument for preservation of the continuum of alternative placements . . . including separate classes and special schools” (p. 166), and noted that “emotional or behavioral disorders are particularly likely to require special environments to meet students’ needs” (p. 166).

In the 2008-2009 school year, the school district where this study was conducted operated 54 segregated special education classrooms specifically for students identified with Severe E/BD, situated within community schools. In addition, a segregated school for students with the most extreme violent behaviours was in operation. (Lil Rueck, personal communication, May 27, 2009). As of August 2008, 1,093 students from Kindergarten to Grade 12 were identified with Severe E/BD as their primary reason for special education eligibility. Students with comorbid disorders who qualified for a different primary eligibility (for example, students with Fetal Alcohol Spectrum Disorder or Tourette’s Syndrome identified under the category of Severe Physical/Medical Disability), and students identified with Mild/Moderate E/BD were not included in this total.

At the start of the 2008-2009 school year, 728 students were placed in the segregated special education classrooms within community schools, and an additional 106 students were placed in the segregated school (Lil Rueck, personal communication, May 27, 2009). Although a small number of the students in these classrooms were identified with a different primary eligibility, these 834 students placed in the segregated classrooms or school clearly represent the fact that, of the 1093 students identified with a primary eligibility of Severe E/BD, most were placed in segregated settings. It should be noted that only one segregated classroom (for students with Severe E/BD with comorbid significant developmental delays) was in operation at the senior high level in addition to the segregated school, meaning that most of the identified students at this level were included in regular classrooms. When taking this into account, it becomes clear that the proportion of students with Severe E/BD placed in segregated settings at the elementary and junior high levels is even higher than the above figures suggest.

Parental Stress

Brennan and Heflinger (1997) used the Caregiver Strain Questionnaire to measure the impact on families of living with a child with a serious emotional disturbance. Three types of strain were reported to exist in the sample: objective strain involving observable stressful occurrences; internalized subjective strain related to negative feelings experienced by the caregiver; and externalized subjective strain experienced as negative feelings toward the child or his/her behaviour (Brennan & Heflinger, 1997). In addition to identifying the types of strain experienced, Brennan and Heflinger (1997) found that families with children differ from families of adults with emotional disturbances in the ways they experience strain.

Numerous studies document the effects of raising a child with severe disruptive behaviour problems on parental stress and depression. Results from a study conducted by Ross and Blanc (1998) indicated that parenting a child with severe behaviour problems is associated with extremely high levels of stress. Goldstein, Harvey, and Friedman-Weieneth (2007) further reported that mothers of children who were hyperactive and oppositional defiant reported significantly higher levels of parenting stress than both mothers of non-problem children and mothers of children classified only as hyperactive. Parents in a qualitative study conducted by Rosenzweig, Brennan, and Ogilvie (2002) identified multiple stressors and difficulties in balancing employment with the care of a child with an E/BD. An additional study (Gartstein & Sheeber, 2004) found that parenting a child who exhibited externalizing behaviour difficulties was predictive of disruptions in family function and declines in feelings of parenting competence, which led to an increase in maternal depressive symptoms.

Perceived Lack of Support

Based on these findings of increased stress and family disruption, parents of children with E/BD may be in need of significant support from sources outside of the family. In most large communities, there is the potential for a wide range of possible supports and interventions to be made available for the provision of direct service to children with E/BD and their families. Understanding and incorporating the parental perspective, including awareness of potentially high parental stress, remains critical to building strategies for effective service delivery. Supports for families, in addition to direct supports for the child, might include parenting programs, information sessions, collaborative meetings, or respite care. It may very well be that these types of supports for the parent and family of the child are as important for the child's continued development as direct supports for the child.

Douma, Dekker, and Koot (2006) gathered information about whether parents of children with intellectual disabilities and psychopathology felt they were receiving adequate support. In this study, 88.2% of parents felt they needed some supports they were not currently receiving, with parents of children with E/BD reporting the most unmet need for support (Douma et al., 2006).

McGill, Papachristoforou, and Cooper (2006) reported similar findings in a study in which family caregivers completed a questionnaire on their satisfaction with support received in dealing with a child's challenging behaviour. Results indicated that most carers expressed dissatisfaction with services received. Themes emerging from the study included experiences of receiving inadequate support and respite provision, perceptions that professionals did not understand the challenging behaviours, family strain, and the experience of a constant battle to obtain support or information (McGill et al.. 2006).

Parental Involvement

It is crucial that parent perspectives are considered not only to find better ways to support parents, but to find means to maintain parental involvement in the child's educational placement, and therefore increase the probability of successful outcomes.

Harvey, Lewis-Palmer, Horner, and Sugai (2003) implemented trans-situational interventions in which appropriate behaviours at school and home were tied together with a behaviour support plan, including supports for the parents. This simultaneous behaviour support resulted in a greater reduction of problem behaviours in both the school and home settings than was achieved by behaviour plans implemented only in the school setting (Harvey et al., 2003).

Nock, Ferriter, and Holmberg (2007) measured the impact of parent expectations on treatment effectiveness and found that the beliefs parents hold regarding the credibility of a program can have a significant impact on their willingness to participate, and potentially on the outcomes of the program. Given this information, it follows that parental perspectives should be incorporated whenever possible into the development of treatment and education programs for children with E/BD.

Contributions of the Present Study

Clearly, children with E/BD and their families are in need of meaningful support in several domains, but current information about how, when, and through whom children and families access these supports is limited. Understanding the parental perspective can help educators, mental health professionals, and other service providers determine what constitutes meaningful support and how it can be provided most effectively. The present study seeks to delve further into understanding the personal experiences of parents of children with E/BD, including information about supports provided through schools and communities, the value of these supports to families, pathways taken to access them, and steps that might be taken to improve this access.

CHAPTER 3: DESIGN AND METHODOLOGY

This study was designed to capture the lived experiences of families of children with Emotional/Behavioural Disorders, with the understanding that family perspectives are a critical piece of working towards building effective support systems. In part, family perspectives have been lacking from current research because of difficulties gaining access to families of children with diagnosed E/BD who are willing and able to share their experiences. While some information can be gleaned from an objective look at records of the services a child and family has received, more in-depth knowledge about the process of acquiring these services, as well as their perceived value to the family, can only be acquired by engaging in a more subjective look through the eyes of the parents themselves. This study endeavours to incorporate both objective and subjective sources of information into a more holistic understanding of the successes and challenges of current services and supports for children with E/BD and their families.

Case Study Research

Case studies are descriptive works, designed to give a detailed picture of a single unit – whether that be an individual, a school, a system, or a community. The knowledge presented is a concrete and real life example or examples, and the context is a vital element in understanding the case. Merriam (1998) asserts that ‘a case study design is employed to gain an in-depth understanding of the situation and meaning for those involved. The interest is in process… in context… in discovery. Insights gleaned from case studies can directly influence policy, practice, and future research” (p. 19). Case studies are both concrete and contextual, and in well-designed research, each of these qualities reveals itself as a benefit. A case can serve to deepen understanding in a descriptive, meaningful form that is not often possible with quantitative or context-free research. Case studies also contribute to the knowledge accumulated on a subject by providing specific examples or non-examples which can support or falsify theory, and therefore stimulate further research and theory development (Flyvbjerg, 2006). Qualitative research, and particularly case study design, often results in rich description with a great depth of information that can help to add weight and detail to the development of a theory. The report of a case study often serves a different purpose than reports of other types of research. Rather than trying to summarize a set of data, the case study report is "an intensive, holistic description … [in which] conveying an understanding of the case is the paramount consideration" (Merriam, 1998, p.193).

Case studies are typically not designed to be widely generalizable, but nonetheless there are strategies any researcher might engage to increase the external validity and applicability of a case to a wider population (Flyvbjerg, 2006). Including rich, thick description provides the reader with sufficient information to determine how the knowledge gained from the study might transfer, by allowing the research consumer to judge how closely their circumstance matches the research context. In the description of cases and subsequent analysis of themes for the present study, every attempt has been made to provide descriptive detail that would enable the reader to do so.

In this study, perspectives are examined using a multiple instrumental case study, or a collective case study, "in which multiple cases are described and compared to provide insight" (Cresswell, 2005, p. 439). One of the benefits of multisite or multiple case study designs is that they can be used to explore and include a greater range of circumstances from which the reader could generalize (Merriam, 1998). In this study the information gathered from the child's Student Records and parent interviews is used to develop a more complete picture of each child and family. The descriptions of the cases and subsequent analysis focus on the pathways taken to access supports, the effects of these supports on the parents' perspectives, and the collaboration that occurred between families, schools, and other service providers.

Participants

In this study, the families of four elementary school-aged children with diagnosed Emotional/Behavioural Disorders participated in qualitative interviews, using a semi-structured interview format. Participants were recruited through Edmonton Public Schools, with recruitment materials sent home with students who were identified and receiving programming for Severe Emotional/Behavioural Disorders, requesting a response to the researcher. The initial distribution occurred through four schools, and was later expanded to a total of fifteen schools. In all, seven families responded to the recruitment and were given more information about the requirements and intent of the study, with four of these families continuing on to participate in the interviews. None of the children or their families had any previous or foreseeable future association with the researcher.

Of the four families, two were single-parent families and two were dual-parent families. Both single-parent families were headed by the birth mother, who had sole custody of the child, and each participated in a one-on-one interview with the researcher. Of the two dual-parent families, one consisted of both birth parents, and one was an adoptive family. In each of the dual-parent families, both parents were interviewed together.

The four families had children attending four separate schools in the public school system, each in a different quadrant of the city of Edmonton. At the time of the study, all four child subjects were placed in special education classrooms providing segregated programming for students with Severe Emotional/Behavioural Disorders within community schools that also provided regular education programming.

An intentional decision was made to include only families of elementary school-aged children, not only to limit the variability in responses, but also because these families had recently been through the initial processes of assessment, diagnosis, and placement, and were able to describe these experiences from recent memory. Of the four families, one of the identified children was in Grade 2, two children were in Grade 3, and one child was in Grade 6. All of the children had received their first formal diagnosis of a Severe Emotional/Behavioural Disorder and subsequent placement in segregated special education programs within the previous two years.

All of the identified children in the families interviewed were boys. This is not surprising given the disproportionate number of boys diagnosed with Severe Emotional/Behavioural Disorders, with some stating that diagnosis is two to three times more prevalent in males than females (Rey, Walter, & Soutullo, 2007).

Data Collection

Merriam (1998) identifies three strategies for data collection in qualitative research: interviewing, observing, and analyzing documents. In case studies, all three strategies are likely to be used. However, one strategy will likely play a more prominent role than the others, guided by the purpose of the study, and the perspectives sought (Merriam, 1998). In the current study, interviewing was used as the primary source of data, with document analysis playing an important and clarifying role. Observation was also employed, although to a significantly lesser extent than the other two strategies.

The four interviews were all conducted by the primary researcher over a period of six weeks from January to March 2009. Each interview was recorded using a digital recording device, and subsequently transcribed solely by the interviewer. During and following each interview, the interviewer also recorded a list of observations and made notes about body language and other cues that may have been lost in the recording.

Questions in the interviews focused on the interactions between the family, school, and community, and the impact of these interactions on supports for the child. Specific attention was directed toward the effects of the child’s disorder on the family and parent, the parent’s perspective on supports provided by the school, the parent’s perspective on supports provided by the community, what constituted meaningful support to the family, and additional supports the parent felt would have been beneficial to their child or family. Additionally, how and when the parent or child accessed supports, and the perceived effectiveness of these supports, were explored. The focus was on obtaining rich, descriptive information that would give insight into personal experiences and perspectives, and that could be directed towards constructing in-depth knowledge about the delivery of effective support systems. The interviews were semi-structured, initially based upon a standard list of questions. These questions were refined and clarified throughout each interview to expand on emerging ideas and to confirm inferences. In addition, each interview concluded with an opportunity for the participants to share any relevant information that had not been addressed previously in the interview.

With permission from the four schools attended, further information on each child's diagnoses, school functioning, and history of supports provided was gathered from Student Records, including psychologist reports, assessments, and school documentation. The interviewer attended each school following the interviews to review the Student Records for each child in their entirety, and this information was used to confirm and expand upon the information gathered during the interviews.

Data Analysis

Data analysis in qualitative research ideally occurs simultaneously with data collection (Merriam, 1998). Doing so focuses the data, limits repetition, and allows the researcher to verify the analysis during the process. The researcher can further contribute to this ongoing analysis by writing frequent comments and notes throughout the data collection, verifying his or her thoughts with the research subjects, and beginning to examine the literature while still collecting data (Merriam, 1998). All of these steps were undertaken in the present research study.

Merriam (1998) asserts that the researcher can also undertake specific methods of analysis that contribute to theory development. One such approach is the constant comparative method, in which a case is constantly compared to other cases, leading to categories and concepts that continue to be compared and analyzed until a basic thematic outline can be developed. In this study, the constant comparative method was employed throughout the analysis, with themes developed from consistent and congruous information that emerged from the data as cases were compared.

All of the data analysis in this study was conducted directly by the researcher, using a word processing program to mark and organize coded data. Interview data, observations, and information from Student Records were initially reviewed several times to provide an overall picture of the constructs. During the coding process, all of the documents were read an additional three times in order to develop and confirm consistent themes and to gather information and direct quotes relevant to these themes.

The researcher must also make a decision about when to stop data collection and begin data analysis. Merriam (1998) suggests that in general, enough data has been collected when the sources have been exhausted, the categories have been saturated so that little new information is appearing, or regularities have emerged. Collecting sufficient information to reach a state of saturation or regularity lends credibility to the results obtained. In the present research, data collection stopped when all responses to recruitment had been followed-up, and the four consenting families were interviewed. As part of the simultaneous data collection and analysis, theme development began during and after the first and second interviews, and while the third and fourth interviews expanded upon and further developed the emerging themes, there was very little evidence from these later interviews to suggest that significant new or different themes should be explored. As a result, it was determined that a sufficient level of saturation to support the major themes had been achieved.

Reducing Bias

Flyvbjerg (2006) responds to the concern that case study research has a bias towards verification with the assertion that in fact, all research contains some bias, which is no stronger in case study research than in other methods. In fact, because of the depth of information gained in case study research, it has a tendency to refute preconceived ideas more often than verify them (Flyvbjerg, 2006). Nonetheless, the issue of bias receives particular criticism in qualitative research because, as is the case for the present study, the researcher him or herself is often the primary instrument for data collection and analysis. However, many steps were taken towards reducing this bias in the present study throughout both the collection and analysis phases.

Parents participated in a brief pre-interview meeting in which the purposes of the study were explained. At this time, participants signed consent forms acknowledging their willingness to participate. Participants were permitted to withdraw this consent at any time up to the submission of the final research report, and no consent was withdrawn.

When conducting interviews, careful selection of the interview questions was employed to help reduce bias. Multiple questions, leading questions, and yes-or-no questions were avoided, in favour of questions that allowed the respondents to express their own perspectives and provide descriptions of their views. In addition, interpretive questions were asked throughout the interviews, in order to verify the researcher's interpretations with the participants. Observation notes were recorded by the researcher immediately after each interview so that as much information as possible was retained from this phase of data collection.

When collecting documents, Flyvbjerg (2006) suggests that the researcher must be cautious to interpret the information in the same frame of reference they were written in. For instance, if the document analyzed is a personal one, it must be seen as a subjective view, and not an objective statement of fact. Every effort was made to interpret documents used for this study in the same context in which they were written. In addition, the authenticity of the documents in each child’s Student Record was assessed to determine their validity and relevance to the current research.

CHAPTER 4: INTRODUCING THE PARTICIPANTS

Case 1: Kevin, Leah, and Nathan

Nathan is the only child of Kevin and Leah, his parents by birth. Kevin works full time outside the home, and Leah runs a day home where she takes care of other children during the week. They live in a house on a quiet street in an older neighbourhood.

At the time of the interview, Nathan was 9 years old and in Grade 3 at his community school, within walking distance of his house, where he has attended since Kindergarten. Leah reported that Nathan doesn't like to listen. She tries to set firm rules and to follow through, but doesn't always feel successful because she often argues with Nathan. Leah and Kevin explained that Nathan has difficulty expressing emotions, gets frustrated easily, and likes to feel that he is in charge. He bangs on things, interrupts, yells, and stomps when he is upset, and Leah and Kevin sometimes feel like his difficulties are almost constant.

History of Supports and Services

Nathan was born two months prematurely, following a difficult pregnancy. He had several operations when he was still an infant, and his parents feel the operations and medical complications contributed to some of Nathan's developmental delays. Nathan continues to have kidney problems and some other health-related issues.

The family moved homes around the time Nathan was 4 years old, and it was around this time that Leah and Kevin started noticing that he was having difficulty listening.

In Kindergarten, his teachers also noticed he was having difficulty, and he was referred to a specialist at a pediatric neurodevelopmental clinic in a local hospital[1]. He qualified for additional early education funding in Kindergarten because of expressive and receptive language delays, as well as delays in fine motor skills, which allowed him to receive some additional support. He was given speech and language service, as well as occupational therapy. He was also given a cognitive assessment, which indicated significant delay in his overall cognitive ability. The assessment suggested that enrolling in an additional year of Kindergarten might be beneficial, and Nathan subsequently repeated his Kindergarten year. In this assessment, there were also recommendations that in Grade 1, Nathan would "likely benefit from an alternative program that provides him with individual or small group support, focusing on basic literacy and math skills."

In the fall of his second year of Kindergarten, as a result of the earlier referral, Nathan was assessed at the pediatric neurodevelopmental assessment clinic as an outpatient. A behavioural assessment was completed, indicating concerns with inattentiveness, hyperactivity, restless-impulsive behaviours, emotional lability, hyperactive-impulsivity, and oppositional behaviours. As a result of this assessment, Nathan was diagnosed with ADHD-Combined type, and the potential use of medication was discussed with Nathan's family. His Student Record indicates that he began medication shortly afterwards. The report from the neurodevelopmental clinic also

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[1] The health region in which this study took place runs two pediatric neurodevelopmental clinics that operate in coordination with one another. The clinics provide in-depth medical and multi-disciplinary assessments of children with developmental, learning or behavioural difficulties that are causing concerns. The clinics may provide direct support to children and their families, and may also refer the child and/or family to additional community or mental health resources. Admission to the clinics occurs through a regional mental health intake process which must be initiated by the families with the support of their medical doctor.

indicates that Nathan was referred for further services through a mental health outreach program.

Nathan's speech and language needs were reassessed at the school in his second year of Kindergarten, and it was determined that he continued to display moderately delayed receptive language and mildly delayed expressive language. Further language intervention was recommended. Nathan received speech therapy at the school for six months, and was then assessed again, with results indicating language skills in the low average range across areas.

Nathan also continued to receive occupational therapy services in his classroom during his second year of Kindergarten, and was reassessed near the end of that school year as having average fine motor skills and mild visual motor delay. A physical therapy assessment completed around the same time indicated that his gross motor skills were in the average range.

A further psychological assessment, including cognitive and behavioural components, was completed at the school in the spring of Nathan's second year of Kindergarten. Results of the cognitive assessment indicated borderline verbal abilities, average non-verbal skills, and low average processing speed, with overall functioning in the borderline ability range. The adaptive behaviour assessment teacher form indicated average adaptive functioning, while the parent form indicated below average adaptive functioning. The report suggested than an Individualized Program Plan (IPP) should be developed for Nathan, and provided recommendations for programming adaptations.

When Nathan was nearing the end of Grade 1, an academic assessment was administered by a psychologist, who noted that Nathan displayed facial tics throughout the assessment and suggested that medical follow-up was warranted. Results of the academic assessment indicated that Nathan was working at grade level in all areas except numerical operations, where he displayed significant delay.

After Nathan completed his second year of Kindergarten, he then began attending a regular Grade 1 classroom. Nathan received another speech and language assessment in the fall of his Grade 1 year, and the assessment results indicated a mild articulation delay, as well as mild receptive and expressive language delays, and a suspected moderate fluency disorder. The speech-language pathologist also reported seeing facial tics throughout the assessment. Following the assessment, Nathan received speech and language intervention services to target language processing. The report indicated that further referral would be made to a regional health service to assist with speech fluency, but no record of this referral or its results was found in the Student Record.

Also in the fall of his Grade 1 year, Nathan was referred by his school to a partnership program between the school and health districts for emotional and behavioural services. An intake assessment and file review was followed by ten individual counselling sessions that focused on attention/concentration and decision-making skills. Consultation with Nathan’s mother regarding parenting strategies and community resources was provided, as well as consultation with the school. His file with the partnership program was subsequently closed.

Nathan was next assessed by a psychologist again at the school two years later, when he was age 8 and near the beginning of his Grade 3 year. The school had requested academic and cognitive testing, and Nathan’s mother additionally requested an emotional and behavioural assessment. The cognitive portion of this assessment indicated overall intellectual ability in the borderline to low average range, with his nonverbal ability more developed than his verbal ability. On the academic portion of the assessment, Nathan displayed average achievement in decoding, with delays in reading comprehension, spelling, written expression, numerical operations, and math reasoning. A behaviour assessment completed at the same time indicated notable conduct problems, oppositional and defiant behaviour, and ADHD symptoms. He was determined to be at-risk for depression, anxiety, and social problems. Examples of his behaviour included arguing, defiance, demanding attention, fighting, being easily frustrated, aggression, dishonesty, and withdrawal. His ADHD symptoms included impulsivity and inattentiveness. This assessment resulted in a diagnosis of ADHD-Combined Type, Severe Oppositional Defiant Disorder, and some features of Conduct Disorder.

Following this assessment, just before Christmas of his Grade 3 year, Nathan was placed in a segregated program for students with Severe E/BD. Because this program was running at his community school, Nathan was able to continue attending the same school he had attended since Kindergarten.

Nathan had IPPs on file for both of his Kindergarten years, when he was receiving early education funding, but no other IPPs were in his Student Record.

Case 2: Susan and Adam

Susan is a single mom of two children, Adam and Mandy. At the time of the interview, Adam was 9 and Mandy was 13. Mandy was attending junior high at a nearby school, and Adam was being bussed to a school in a neighbouring community, where he was in Grade 3. Susan, Adam, and Mandy live in a rented townhouse in an established neighbourhood. Susan works slightly less than full time to accommodate her children’s school schedules, and reported her income at under $20,000 a year. Adam`s dad has seemingly had no involvement in his life since he was a year old.

Susan described Adam as intelligent, but he has difficulty listening and refuses to do anything at home. She reported feeling that when she tries to be firm with him, it has the opposite effect of what she intended. Adam needs a lot of individual attention. He also has bouts of violence at times, where he hurts or threatens to hurt Susan and Mandy, and breaks things. In addition, Adam sometimes displays obsessive-compulsive tendencies, like focusing excessively on one type of toy or movie.

History of Supports and Services

Susan described Adam as an infant and toddler who had few problems and an easy going personality. She noticed that when he had a temper, she would have to physically hold him, but at the time, didn’t feel it was anything major.

Before beginning school, Adam was in daycare. The documentation in his Student Record reports that he received extra staffing and support at his daycare through an early education program. After being assessed at the daycare at age 3 years, 9 months, Adam received speech and language services through a community health program. He had average language skills and a mild articulation delay, which did not qualify him for additional funding through this program. In the assessment, it was noted that Adam would benefit from an occupational therapy assessment and a mental health assessment. There is no record to indicate whether this recommendation was followed.

Susan, Adam, and Mandy moved to another city for a year, and Adam was enrolled in Kindergarten. Adam struggled at school, and Susan chose to take him out of the Kindergarten program that year, believing that he was too young. The family moved back to Edmonton, and Adam started Kindergarten again the next fall at his community school.

The following year, Adam was enrolled in Grade 1 at the same school, and placed in a Grade 1 and 2 split class. Adam's teacher reported that he was displaying behaviour difficulties, and Adam had a psychological assessment completed at the school in the fall of his Grade 1 year. A cognitive assessment was done, with Adam's overall abilities noted to be in the average range, with low average scores on measures of his processing speed. The Behaviour Assessment Scales for Children were completed by both his mother and teacher, and Adam was noted to be in the Clinically Significant or At-Risk ranges in all areas by the teacher, and to be in the same ranges by his mother on all but one scale. An academic assessment was also completed at the school at this time, and a list of recommendations was provided. In the assessment, it was noted that Adam's mom had contacted a regional mental health service, which had in turn suggested further assessment at a pediatric neurodevelopmental clinic as an option. A copy of the assessment was forwarded to the regional mental health service, and Susan also signed a release form for the school to share information with a community centre where Adam was receiving counselling.

Adam has had an IPP in place since December of his Grade 1 year. In his IPP, it was documented that a behaviour specialist observed Adam at the school in Grade 1 and assisted with his IPP. In January of Grade 1, a full time educational assistant was assigned to help Adam in his classroom for three weeks. Adam's Student Record documented that physical aggression continued with the full time aide and behaviour management strategies in place. The teacher noted that his time outs "didn't diminish over time and his academic progress was severely impeded by his own noncompliance."

Adam was admitted to an assessment classroom at the pediatric neurodevelopmental clinic in January of that same year for a 3 week assessment.[2] During his time in the assessment classroom, he received an occupational therapy assessment where he was assessed to have below average motor skills, low average visual motor skills, low average visual perceptual skills, and poor printing skills. A speech and language assessment revealed that Adam had average receptive and expressive language skills, but low average higher level language skills. Results on an academic assessment determined that he was low academically in all areas. As prescribed through a psychiatrist associated with the assessment classroom, Adam began taking Risperdal and Luvox medications at home. While Adam was attending the assessment classroom, his school placement moved from his neighbourhood school to a school in a nearby community with a segregated program for students with Severe E/BD. When Adam was discharged from the assessment classroom, he began attending the segregated program.

The next fall, when he was in Grade 2, Adam was admitted for a further 12 week session in another assessment classroom at the same neurodevelopmental clinic he had previously attended. He then returned to the segregated classroom where he had completed Grade 1. Adam's Student Record noted that a discharge meeting that was to occur with the neurodevelopmental clinic staff and Adam's classroom teacher was

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[2] The assessment classroom is a 3-week program where children are admitted for day treatment and attend school at the pediatric neurodevelopmental clinic. During the program, multi-disciplinary assessments are administered for diagnostic and treatment purposes. Nurses, mental health therapists, psychiatrists, social workers, occupational therapists, and speech language pathologists may all be involved in observation and intervention during the 3-week program, and parent involvement is also mandatory. If additional treatment is deemed necessary, a child may participate in a 12-week extended program. Admission to the assessment classroom must be facilitated by a child psychiatrist at the neurodevelopmental clinic.

cancelled and did not occur. A follow-up teacher questionnaire was later completed by the teacher and returned to the pediatric neurodevelopmental clinic. One of the recommendations of the neurodevelopmental clinic was that Adam use assistive technology (an Alphasmart) in his classroom. This was provided by a children's disability fund, and Adam's Student Record indicated that it was implemented in the classroom for a short time, but was not continued after some parts were misplaced.

Susan reported that through the neurodevelopmental clinic, Adam was initially diagnosed with Tourette's, and then later assessed as having features of Tourette's Syndrome, Asperger's, Obsessive-Compulsive Disorder, Oppositional Defiant Disorder, and other learning difficulties. His Student Record had no documentation of a formal diagnosis. His IPP indicated that he was showing some signs of anxiety and compulsive behaviours. Adam continued to be seen regularly by a psychiatrist at the neurodevelopmental clinic, who took over Adam's case when he was in the assessment classroom.

Adam has limited vision in one eye, and he wears glasses. At the time of the interview, Adam had recently been seen by a physician, after having some difficulty breathing. Following an MRI, Susan reported that Adam was diagnosed with periventricular heterotopia, a brain malformation resulting in his cerebellum being larger on one side than the other.

Adam continued in the same segregated special education classroom for Grade 3. A request for social work support was placed in the fall, but there was no record of service. His school also placed a referral for Adam to receive updated cognitive and behavioural assessments, which were in process when his Student Record was reviewed.

Case 3: Allison and Ben

Allison works full time, and Ben is Allison’s only child, born when she was 20 years old. At the time of the interview, Ben was in Grade 2. Allison and Ben had been living in a townhouse on their own for 4 years, after an abusive relationship between Allison and Ben’s father ended. Ben’s father passed away 3 years previously, and had no contact with Ben in the year prior to his death. Their extended family lives out of town. Allison has another long-term partner, and she spoke of their plans to marry. He is active in Allison and Ben’s lives, but was not living with them.

Allison described Ben’s behaviours as falling on the high functioning end of the autism spectrum. She explained that Ben’s psychiatrist had been reluctant to label him with a specific disorder because his symptoms fall under so many different possible diagnoses and no single diagnosis appears to capture his range of needs. The psychiatrist did, however, provide a diagnosis of ADHD so that Allison and Ben could qualify for some specific funding and programming. Allison reported that Ben is sometimes angry and violent, and that he has broken things in their home. He likes attention, and is quite good when he is one-on-one with an adult. However, he sometimes has tantrums at school, where he kicks things, bangs on walls, and needs to be put into segregated time out. He shows little empathy for others, and has difficulty understanding right and wrong or the relationship between actions and consequences.

History of Supports and Services

When Ben was in daycare before he started school, Allison noticed that he wasn’t really listening. Allison thought that it might be emotional difficulties related to his parents' break-up and the events that followed. She took Ben to a doctor, who told her it was probably nothing, but put in a referral to a pediatric neurodevelopmental clinic.

Ben began attending Kindergarten at his neighbourhood school, and at the time of the interview, was attending Grade 2 at the same school. In Kindergarten, he received extra funding through an early education outreach program. He had a daily communication book in place, as well as an IPP. His IPP noted impulsive, defiant, and argumentative behaviour. It also noted that he was on medication for ADHD, prescribed by a psychiatrist at the neurodevelopmental clinic. During his Kindergarten year, Ben's IPP stated that he had access to an OT, a psychologist, a school family liaison, and an in-class behavioural assistant at the school. His mother also attended all of the IPP meetings.

During his Kindergarten year, Ben was assessed several times. A developmental screening for motor skills, concepts, and language completed early in the school year indicated there was a need for follow-up around Ben's motor skills. Another assessment that followed recommended that he receive occupational therapy services, noting that he had average fine motor skills, with some weaknesses, and that he displayed attention and sensory processing difficulties. He received occupational therapy services, and his final assessment noted average visual motor integration skills, as well as ongoing sensory difficulties, and some motor coordination difficulty.

A psychological assessment was completed at the school in the fall of Ben's Kindergarten year. It noted that Ben had been asked to leave two daycares, and then was reaccepted to one with an aide. The psychologist interviewed Allison for the assessment, and stated that she had pursued counselling for Ben, but that it was limited to one session. Allison had already discussed her concerns with a psychiatrist at the neurodevelopmental clinic, who had begun a referral for further assessment. The cognitive portion of the assessment completed at the school indicated that Ben scored in the average range on the verbal, performance, and overall scales, and in the low-average range on the processing speed scale of an intelligence test. On a behaviour rating scale, Ben was in the clinically significant range for externalizing problems, behavioural symptoms, atypicality, and attention problems. His adaptive skills were in the at risk range; internalizing problems in the at-risk to average range; and withdrawal in the at-risk to clinically significant range. The assessment suggested Ben displayed features of ADHD.

An application for Ben to receive funding at the school for Severe E/BD was made near the end of Ben's Kindergarten year, but was denied because no official diagnosis had yet been made. Regardless, it was noted in his IPP that all team members agreed to a placement in a segregated program for students with Severe E/BD the following year. He was subsequently given a diagnosis of Severe ADHD and ODD by his psychiatrist at the neurodevelopmental clinic, with the features of poor impulse control, hyperactivity, poor concentration, defiance, volatile mood, verbal and physical aggression, and difficulty with social interactions and problem solving.

Ben's placement in the segregated program for students with Severe E/BD began in September of his Grade 1 year, in the same neighbourhood school where Ben attended Kindergarten. When he was in Grade 1, Ben's classroom had 7 students, with a teacher and an aide.

Ben attended an assessment classroom at the pediatric neurodevelopmental clinic for three weeks in the middle of his Grade 1 year. During his time in the assessment classroom, Ben was assigned a different psychiatrist, as well as a school family liaison.

He underwent a change in medications and was prescribed Neuleptil and Dexedrine. An academic assessment showed average academic skills in all areas. An assessment of intelligence resulted in average performance scores across all areas (verbal comprehension, perceptual reasoning, working memory, and processing speed). A speech assessment showed a mild expressive language delay and a mild higher level language delay. His discharge report contained some follow-up recommendations for working with Ben.

After Ben completed the three week program in the assessment classroom, he was admitted to a longer-term cognitive health and intervention program at the same hospital, where he attended school for an additional three and a half months.[3] During his time in this program, Ben was in a class of seven students in Grades 1 through 4, in an adapted behavioural program. Ben had an IPP. Ben's discharge summary from the cognitive health and intervention program noted that he worked on social skills with the nursing staff and an occupational therapist, and noted growth in both his social and behavioural skills. His occupational therapy summary through the same program noted that Ben had below average visual-motor abilities, and average motor skills, and suggested that Ben may need modified expectations in the area of written output. The occupational therapy report also noted that Ben was previously diagnosed with ADHD and Tourette's Syndrome, although this diagnosis was not confirmed elsewhere in Ben's Student Record.

Ben returned to the segregated special education program at his neighbourhood school for the last month of his Grade 1 school year, and continued there for Grade 2.

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[3] The cognitive health intervention program is a day treatment program for children with complex mental health issues and, unlike the assessment classroom, has no specified time limit for a patient's stay.

Ben had IPPs in his Student Record for every year since he was in Kindergarten. His IPP for his Grade 2 year noted that he was achieving at or above grade level, and his goals included improving relationships with his teachers, peers and others, developing greater control over his own behaviours, and increasing his writing skills.

Ben's IPPs consistently documented that his mother was very involved and supportive of his programming. She signed a consent form for his psychiatrist at the neurodevelopmental clinic to communicate with the school for as long as necessary. Ben's teacher stated explicitly in the IPP that she was "available to conference with outside community health and counselling agents, when needed, by phone, letter or in person," and his Student Record included conference summaries where Ben, Allison and the teacher had set goals together.

Case 4: Gary, Carol, and James

Gary and Carol adopted James, their only child, at birth. Gary and Carol both work, and they live in a bungalow on a quiet street in a mature neighbourhood. At the time of the interview, James was 11 years old, and in Grade 6.

Gary and Carol described James as intelligent, with a good conscience, and an ability to make friends easily. He reads very quickly and has a lot of energy, but he struggles with independence when he is doing work, and they characterized him as immature. He does everything very quickly and often sloppily, and it takes a lot of effort for him just to get anything down on paper. He is involved in several extra-curricular activities, including piano lessons, hockey, tae kwon do, and swimming lessons. Gary and Carol reported that James sometimes tantrums or expresses defiance at home, but they feel it is more out of frustration than opposition. When he was younger, he would pout and could not be reasoned with once something upset him.

History of Supports and Services

James was very active from birth, and was hard to keep calm. He liked to be bundled up, and needed white noise in the background in order to sleep because anything else would disturb or distract him. Gary and Carol reported that by the time he was 3 years old, he would hang off of things and seemed to be in constant motion, but that he also appeared very intelligent.

James completed Kindergarten through Grade 5 in the same school, in a French Immersion Program, and was not coded or funded for special education during this time. When James was in Kindergarten, his teachers indicated that they had concerns about his level of activity and spoke to Gary and Carol about having James assessed. James' pediatrician asked the teachers to complete a behaviour rating scale and questionnaire. This process was completed again the next fall, when James was in Grade 1. Diagnostic outcomes of these assessments by the pediatrician were not found in James' Student Record. Gary and Carol indicated that the pediatrician said James probably had ADHD, but the pediatrician felt he was too young to label at the time. Some suggestions to deal with ADHD, distractibility, and impulsivity were placed in James' Student Record as a result.

The pediatrician also referred James to a local hospital child health clinic near the beginning of his Grade 1 year, where an occupational therapy assessment was completed. The assessment indicated superior fine motor skills, and age appropriate visual-motor integration, visual perceptual, and motor coordination skills.

On the advice of their pediatrician, Gary and Carol made a decision to start James on the medication Concerta when he was in Grade 2 or 3. James' parents felt his Grade 3 year was one of his most successful years in school. However, they were concerned about the side effects of the medication, and James had reached the maximum dosage for Concerta within a year, so they stopped administering this medication when he was mid-way through Grade 4.

An academic assessment was first completed when James was in Grade 4, at the beginning of the school year. This was completed at the school by a reading specialist accessed through the school district. It indicated that in most areas, James was working at or above his grade level.

Cognitive and psychological assessments were also completed the same fall. On the cognitive assessment, James displayed average to high average abilities in all areas except verbal comprehension, which was in the low average range. The psychological assessment was not available in James's Student Record, but was referenced in other documents. According to these documents, the assessment indicated that James had been placed on medication and was seeing a counsellor for behavioural concerns.

An occupational therapy assessment was completed at the school in April of James' Grade 4 year. The therapist set goals for James in the areas for attention skills and writing in class, and James received eight sessions of occupational therapy support at the school over the next two months.

An emotional and behavioural specialist also became involved with James and his family at the school near the end of James' Grade 4 year, to help with emotional concerns. In May, the specialist met with Carol, and it was decided that the family and school would complete some behaviour screening tools. There was no record of the outcome of these assessments on file. The specialist assisted the school and family with a referral to a pediatric neurodevelopmental clinic. In addition, James received individual service from the specialist for three months the next fall, when he was beginning Grade 5. The specialist then discontinued service to James.

There is a limited record at the school of any services received as a result of the referral to the neurodevelopmental clinic, documenting only that James was referred for further occupational therapy assessment by a doctor at the clinic, which occurred over the summer between James' Grade 4 and Grade 5 years. This assessment determined that James was displaying below average fine motor control and a moderate delay in visual motor control. A sensory profile was completed, which indicated that James perceives and reacts to some sensory information atypically. The report included a long list of recommendations and suggestions to help James with sensory, handwriting, fine motor, gross motor, visual-motor integration, visual-perceptual, and keyboarding skills.

James was next assessed in the second half of Grade 5, when he was given cognitive, academic, and behavioural assessments. The cognitive assessment indicated that James' overall functioning continued to be in the average range, but that his verbal comprehension remained below average. The assessor concluded that James's school difficulties were related to attention and sensory deficits, not overall cognitive deficits.

On the academic assessment, James academic performance was in the low average range for spelling and math. The assessor noted that even though James scored in the average range for written language, his writing was also an area of need because it was less sophisticated than would be expected from a Grade 5 student.

Teacher and parent rating scales and a classroom observation were completed as part of the behavioural assessment. A list of concerns noted by the teacher indicated that James was easily frustrated or angered, would hide to avoid doing work, had a very short attention span, had difficulty following rules and routines, struggled with written work, had difficulty with fine-motor skills, had loud outbursts, made noise continually, had poor organization skills, had difficulty working in a group, usually fidgeted, laid or crawled on the floor, and could be very argumentative and oppositional if he was asked to do something he didn't want to do. The results of the behaviour scales completed by the teacher indicated that James was functioning in the clinically significant range in the areas of hyperactivity, aggression, conduct problems, anxiety, depression, attention problems, learning problems, atypicality, and withdrawal. On the behaviour scales completed by Gary and Carol, James was assessed to be functioning in the clinically significant range in the areas of hyperactivity, depression, and attention problems; in the at-risk range in the areas of conduct problems, anxiety, somatisation, atypicality, and withdrawal; and in the average range in the area of aggression. As a result of this assessment, it was determined that James met the criteria for Oppositional Defiant Disorder at a Severe level, and that he also met some of the criteria for Conduct Disorder.

Following these assessments, James was placed in a segregated program for students with Severe E/BD. Because this program was not available at the school James attended from Grades 1 to 5, James began attending the special education program at a new school in September 2008, at the beginning of Grade 6. In the summer before he started Grade 6 in the segregated program, he also began medication again, taking Stratera for anxiety and attention difficulties.

At the time of review, there were no IPPs found in James' Student Record.

CHAPTER 5: UNDERSTANDING THE FAMILY IMPACT

There is no doubt that a family is impacted significantly when a child is diagnosed with a disability, although the extent and form of this impact varies depending on a multitude of factors. Parents in the present study repeatedly expressed the immense personal impact of parenting a child with E/BD, from the earliest signs of behaviour difficulties, through their daily lives, and extending into their planning for the future.

Early Signs

When asked about their first indications of behaviour difficulties in their children, all of the families could identify in retrospect some early behavioural problems at home or in their parent-child interactions. In two of the cases, parents noticed difficulty but didn't think the behaviours were abnormal, assuming that the behavioural problems they were noticing were either a passing difficulty or a reaction to family circumstances. When describing Adam's early childhood, Susan explained:

> He was really easy going, but when he did get that temper, I would have to hold him, but I just thought okay well this child is really a brat or something, you know? But I didn't really think much of it.

In Allison's similar experience, she said Ben:

> …started kindergarten three years ago, and that was when everything kind of came about, that this was more than just me not being a good parent and the emotional side of things. So I thought it was just kid stuff and me not being a consistent parent, because all I wanted to do was coddle him after everything that happened. So when his current kindergarten teacher suggested it could be more than just that and that maybe we should look at some testing, things started

> coming about that you don't really notice because you think it's just, like he's just Ben. So you don't think it could be anything serious.

Neither Susan nor Allison sought help for their children before difficulties were raised by the school.

In the other two families, the parents sought help on their own either before their child entered school, or in Kindergarten. However, their original inquiries at these times did not receive responses that led to further assessment or intervention. In Leah's recollection of first seeking help and trying to understand Nathan's behaviours, she said:

> I used to walk him to school every morning and I said, you know, I think I have to get his hearing tested, because I'd call to him, and it was almost like I had to yell to him to get him to respond back to me. So I mean, I got everything checked out for him and everything was fine. But I was [wondering], "So why is he acting like this?"

Despite Leah and Kevin's concerns, no further assessment proceeded as a result of these early inquiries.

Gary and Carol also noticed James displaying unusual behaviours and sought help, and Carol reported that from the time James was about three, she:

> …was convinced there was something unusual about his behaviour compared to other three-year-olds. He would hang off of anything he could get his hands around, and he was just constant. From the time he would get up in the morning till the time he went to bed, it was just constant go.

When they took him in to see a pediatrician, "his pediatrician had said he probably had ADHD. But… he felt he was too young to label." No follow-up to this initial interaction with the pediatrician was done until Gary and Carol sought further help after James experienced continued difficulties in Kindergarten. The findings in this area are consistent with those in a study with a much larger sample (Fanton, MacDonald, & Harvey, 2008), which indicated that about half of families of children with behavioural difficulties that persisted into the school years consulted with their pediatrician before the child reached school age, and of these families that sought help, less than half were referred to further services at the time of initial consultation.

All of the families were surprised by the extent of behavioural challenges their children displayed once they began school, and described the difficulty they had coming to terms with the ongoing difficulties and the realization that the behaviours were abnormal and were affecting the child’s functioning at school. Susan described her initial reaction to the school’s reports of Adam’s behaviour, saying “It was like, it was a shock to me, because it was like this isn’t my child, you know? My child… he wouldn't do that, you know?” and went on to detail strained relations between her and the school that originally initiated further assessments. Carol, despite recognizing James’ hyperactivity at an early age, was still surprised by the effects at school, saying:

> I knew there was something. But I didn't, at that time, realize how it would affect him academically. And I didn't realize all the… other issues that it would bring up. Like sure he's got lots of energy and has trouble focusing, but it didn't occur to me that it would bring up issues with disturbing the class and, you know, things like that.

Susan explained further the emotions related to accepting that Adam’s behaviours were problematic as she said:

> I just thought, okay, that's a boy thing… I never thought it was, you know, that's what Autism does, or this is an Autism thing. Like I just (thought), I don’t know, it's a boy thing, it's a kid thing, you know? And you don't want to. It's your child and you think, as much as we know they’re not even close to perfect, in your mind, you know, they're perfect. And then you hear this… you don't love them any less, but you think that’s not how they're supposed to be.

Leah similarly described her reaction after Kevin went to a meeting to hear the results of an assessment completed at school, saying:

> He (Kevin) brought home the paperwork and was reading it to me and telling me everything. It was like yeah it was borderline and everything. And I started to cry when he told me that. I was like oh my god, not mine.

As evidenced by these accounts, schools are a very likely place for the first indications of E/BD. Although it may sometimes seem to educators that it would be difficult not to notice the presence of a Severe E/BD at home prior to starting school, it is important to realize that even when parents notice behavioural challenges, these difficulties may not stand out enough to prompt the parents to seek further help. Additionally, even when further help is sought by the families, there may be some reluctance on the part of practitioners to pursue in-depth assessment prior to beginning school, as was the case for both Nathan and James. As such, schools are frequently the first source of information about a child’s mental health. This has implications for the way that information is communicated to families, and the extensive resources that might be required to facilitate early assessment and intervention on the part of both schools and families once behavioural difficulties have been identified. It also speaks to the sensitivity required by educators, administrators, and others communicating this information, given the strong emotional reactions that can be expected from parents in response to these early signs of E/BD.

Lasting Effects

The effects of parenting a child with E/BD understandably last well beyond the initial identification of behaviours, sometimes affecting nearly every aspect of the parents' life. The families interviewed expressed with clarity the long term impact of each child's behaviour difficulties on their levels of stress and feelings of guilt and blame. In addition, parents spoke about the general impact on their work and family decisions, their need to take on an advocacy role for their child, and the effects of their child's difficulties on their outlook for the future.

Parenting Stress

As explored in the review of the literature, the relationship between elevated child behaviour difficulties and parental stress is well documented. In the present study, this theme was also clear throughout all of the interviews. When asked how their child's behaviour has affected them as parents, every one of the parents gave a response indicating elevated stress levels. In their daily lives, the experiences of strain related to coping with their child's emotional swings, defiance, and incidents of aggression or violence were clear. The results of Ditrano and Silverstein's (2006) study, which similarly explored the perspectives of parents of children with E/BD, mirrored these results, finding that multiple stresses were experienced by these parents, and that they "felt helpless and overwhelmed because they did not know how to deal with their child's challenging behaviours and school failure" (p. 363).

Leah and Kevin expressed their frustration with the feeling that they are always arguing with Nathan, and with the seemingly constant nature of these arguments throughout daily routines. In Kevin’s words:

> Sometimes I’ll leave in the morning and they'll be arguing because he doesn't want to go to school… I'll come home and they'll be arguing over something else. They'll be having problems with work and whatever else, but it's just it always seems to be one fight after another. He doesn't want to do his homework and then he doesn’t want to eat his supper and he doesn't want to get ready for bed and he doesn't want to brush his teeth.

Allison also related her stress over what would otherwise be routine activities in the community. She explained:

> I don't go out in public very often at all. We don't go to public events, because he acts out. Grocery shopping is stressful. I try to find something to distract him while we go grocery shopping. Like I give him the list or a calculator and try and get him to add things so he's focusing on something else. But he can be embarrassing. People look at me.

She went on to relate an event when she had to leave groceries behind and return home before finishing because Ben had acted out. Allison sensed her own fear and embarrassment over Ben’s behaviours, and explained some of the coping strategies she had used to help manage these feelings, but reported that they were still persistent in her daily life.

For Gary and Carol, their stress was expressed as a feeling of exhaustion, and Gary described their experiences with James as:

> …almost like you have to be his external brain. A lot of times you're thinking for him. So it's tough. You have to think for him all the time. You have to… And it's the same thing all the time. It's constant right? So it's kind of a strain on us. It *is* a strain. Not kind of a strain, it *is* a strain. [italics added]

This feeling of constant difficulty, with little reprieve, was consistent throughout all of the responses.

For Susan and Allison, who displayed the most concern about the sometimes violent behaviours in their children, the sense of stress also carried over into their feelings that they or their belongings are not always safe at home, and their own reactions to these aggressive incidents. Allison described an incident where Ben threw something at her television and broke it. Susan displayed a sense of helplessness, as she explained that:

> Everything I have is being broken, wrecked, and I can't get mad, but yet I am getting mad. … It's frustrating because you work so hard for this stuff, and then he just comes through there no big deal, you know.

Some of the participants also communicated the significant impact this ongoing stress has had on their own mental and physical health as parents. Allison reported long term chronic insomnia, noting the stress of feeling like she has no control over Ben's behavioural difficulties keeps her awake and affects her self-esteem. She noted that she is "a lot more intense at work," and that she feels irritable and easily annoyed by others. Following the onset of Adam's difficulties at school, Susan described her experiences facing a mental health crisis of her own, and recounted that parents:

> …forget about ourselves, and especially emotionally. And unfortunately, I stumbled and I fell. Like, I went into deep, deep depression, because I was so

> busy looking at what he needed, I totally didn't see what I needed. And it even took me a while to see that, because even when I thought I was okay, I still wasn't looking after myself. I wasn't eating right. I wasn't sleeping right.

She went on to explain the continued effects on her health, including the feeling of “getting burnt out.”

Feelings of Guilt and Blame

As a factor in their stress and personal coping with their child’s E/BD, parental feelings of guilt and blame were pervasive and explicit throughout the interviews, in speaking about trying to understand the causes of a child’s disorder, in the behaviours the child displayed at school, and in asking for help. The participants frequently recalled either blaming themselves for their child’s difficulties, or feeling blamed by others. The most common reaction from parents was thinking their child just needed better discipline or more love, or that the behaviours were a result of inconsistent parenting. Participants also expressed being angry at themselves for the way they handled behaviour, thinking they were either too easy on their child or reacted too quickly to behaviours. In addition, all of the natural parents felt some guilt about the possibility of a genetic component to the behaviour difficulties experienced by their child. The reactions of others, including extended family, seemed to compound these feelings of guilt and blame.

In addition, parental stress was impacted by the experiences and reactions of others outside the family, including the school. As the parents interviewed explained incidents of misbehaviour at school, they often expressed their own remorse for their child’s behaviour, conveyed their feelings of guilt, and explained that their initial response had been to say “I’m sorry,” in effect taking the weight of responsibility for their child’s difficulties. Two of the parents specifically recounted a sense of dread when they knew the school was calling, and related this dread to their own feelings of guilt and blame. Crawford and Simonoff (2003) found these same feelings of guilt and blame were expressed by parents of children with E/BD in their study, who also reported feeling isolated and marginalized by their children’s difficulties.

When discussing their experiences seeking help and support outside of school, guilt continued to be a commonly mentioned factor, in the sense that families expressed reluctance to ask others to care for their child with E/BD or to provide support. Allison expressed her concerns about putting him in the care of others when she said:

> He's my responsibility. I don't want him to be anybody else's responsibility. It makes me nervous leaving him with someone because they don't know what he's going to do in their house. I don't know what he could break, if he's [going to] have an episode where he's going to get angry and something's going to end up broken. I am fearful to go pick him up sometimes at day care.

Leah expressed the same concern, explaining, “I don't like putting him on people. I just, I feel bad. Like, I mean I don't go out and get babysitters all the time, because I just feel bad, because I know what he's like.” All of the families mentioned incidents where they had given up opportunities or refused help because of this sense of guilt or fear of burdening others. These feelings are likely to compound stress, by limiting parents’ willingness to seek or accept support, and sometimes virtually eliminating opportunities for parents to have respite from caring for their child or to experience social fulfillment of their own.

Impact on Work and Family Life

The impact of a child's behavioural difficulties sometimes extends beyond stress and emotions to directly affect major life decisions. The most common larger impact mentioned by the participants was on their employment, in part because of difficulties acquiring adequate child care. For Leah, Nathan's difficulties led her to open a day home, so that she could care for other children in her home and still be available to meet Nathan's needs. For Allison, it meant that sometimes she had taken Ben to work with her, and at one point had to negotiate with her employer so that she could go in to work for only 2 hours a day and work from home the remainder of the time while they waited for Ben to receive funding for an aide to accompany him to daycare after she was told he could not return without one. Susan lost her job altogether because of the impact Adam's behaviours and the phone calls to pick him up from school had on her ability to work. She was unable to find an aide for Adam to go to daycare, and eventually took a different job with fewer hours and greater flexibility so she could arrange her work hours around the times Adam's school bus picks him up and drops him off. Brennan and Brannan (2005) reported that greater caregiver strain from missed work due to a child's behaviour was associated with lower likelihood of parental workforce participation, and the parental responses in the present study corroborate these results. The responses are also consistent with those found in a study that reported that the responsibilities of caring for a child with E/BD significantly shaped parental employment decisions, and particularly impacted the number of hours of work they engaged in (Rosenzweig, Brennan, Huffstutter, & Bradley, 2008). This same study noted that parents of these children require jobs that afford them the flexibility to be available and respond to their child's needs during work hours, and that such work-life integration issues contributed to parental stress (Rosenzweig et al., 2008). Inadequate access to child care further contributes to parental stress (Brennan & Brannan, 2005), with parents of children with E/BD less likely to access the child care settings typically used by other families outside of school, and more likely to care for the child themselves, in their own home (Rosenzweig et al., 2008).

For family life, the impact of a child's disordered behaviour is also far-reaching, affecting both large and small decisions in their daily lives. Leah and Kevin had planned to have another child after Nathan, but Leah said of the impact of Nathan's early difficulties:

> It's been stressful. I mean… we were trying for a bit to have another child. I'm like, you know what, I don't want any more kids if they're going to end up… I was so stressed… I mean, I wouldn't change it for the world but you know, it was really stressful.

Three of the children involved in this study had no siblings. Susan, a parent of two children, recounted that Adam's high need for attention has left her feeling like she doesn't give enough attention to her daughter. She also described the struggles her daughter has faced in trying to cope with Adam's difficulties, including being kicked and punched during Adam's outbursts.

But the impact also affects families in smaller ways that stretch through everyday life. Allison spoke of the inability to do anything spontaneously, because of Ben's rigid nature and his need to be prepared well in advance, and of the dangers Ben has put himself in because of impulsive behaviours. Carol and Gary spoke of the excessive time it takes to get James ready to go out or to complete simple tasks, like unpacking his lunch bag, because he needs so much guidance to follow through each step. Susan spoke of the considerations she's had to make because their home is rented, and allowing Adam to have a "full-blown episode" could threaten their ability to continue living there. Clearly, the impact on families is deep and pervasive, sometimes affecting nearly every aspect of their lives.

Advocacy

The families interviewed also expressed that they were affected by their changing roles related to their child's behaviour, particularly by the need to become a seemingly constant advocate for their child's needs. This finding was consistent with that of Grace and Russell (2005), who conducted similar qualitative research examining the perspectives of parents of children with Tourette's syndrome, and found that advocacy arose as a consistent topic among all of the participants. In their description, "Parents re-defined their parenting role to include being the voice for their child within the school system" (p. 51), as a result of having a child with a disability. Similarly, in the present study, all of the parents felt that while they did not always initiate assessment, they were almost always the ones to initiate steps towards support or intervention for their children. While talking about his and Leah's constant involvement in seeking support, Kevin explained:

> There would be some problem that would come up so she would get a hold of somebody at the school and say, "Okay well what should we be doing or what can we do?" And they'd recommend a test or a specialist or somebody. And then we'd go from there, and everything takes time. So we'd try that for a while and then we'd wait for the next problem to come up, or results or something to come

> from that and try that for a while. And then something else would come up so then we'd ask again, “Okay well, is there anything else we could be doing?”

In the end, they felt that Nathan only received both assessment and support for his behavioural difficulties because they kept trying and asking questions, and that the school eventually was “giving in”. They phoned other schools, doctors, and school district administration for support. Leah described the persistence required, explaining “…you have to call them every single day and say I need this done until they do it… I'm not good at that all the time.”

Susan, feeling confused by the answers she was getting from professionals, and thinking that she didn’t have anywhere else to turn, began to pursue other routes to better advocate for Adam. She went to the library to sign out books on different disorders, choosing to educate herself so that she could speak to doctors, teachers, and school administration with the background knowledge she gained after doing her own research. She read books and searched online, finding that these sources helped her to better understand, and to ask questions about the assessments, diagnoses and supports Adam received.

When asked what had worked for her when trying to get help for Ben, Allison clearly described the constant questioning she engaged in to advocate for Ben, as she responded:

> I think standing back and waiting for somebody to give you an answer doesn't work. You have to be calling on a constant basis. “Has anything happened here? Has anything happened here? What's happening with this? Is this going to happen?” Like staying on top of it was kind of the only thing that helped me get

> through.… I was constantly calling the doctor's office. “Has the referral gone through? Am I going to get an appointment anytime soon?”

She went on to recount questioning the doctor, the staff at the neurodevelopmental clinic Ben was referred to, the teachers, and the psychologists, asking questions about when services would be received, how to move each process along, and how to facilitate communication between the different services. She concluded by saying:

> That’s just honestly the only way you're going to get through it. If it seems like a big thing, tell them it's big. If it seems like a small thing, still tell them it's big. They will listen to you faster if you tell them “I'm really, really worried about this.” But just saying “Oh no, it's been okay,” then they're really going to think that it's better when it's not.

Allison also expressed her need to constantly think ahead in order to prepare for changes in Ben’s life and to put the supports in place ahead of time. Allison, in preparing for a change in Ben’s school still a year and a half away, described the fall-out of this change, because it means she also needs to make a change in daycare, which means finding Ben a new aide for daycare and a change in transportation. All of these might mean new routines for Ben that require her to start thinking ahead far enough in advance to coordinate all of these changes and do her best to make them successful for Ben. She said she keeps lists in order to organize all that needs to be done to plan ahead. Even as she talked about the successes of the past, the need to continue to advocate for the future pressed in as she said, “I want to be proud about it, but really just all I can think of is, ‘Okay what's the next step? What do we do now? Like how do we make it easier for him?’”

Gary and Carol also articulated the need to be thinking ahead, as Gary said “You always want to be proactive, right? So you're always trying to think of ways that you can teach and give him the skills so that when he's confronted with something that he'll be able to handle it.” He also described one of their attempts to be proactive in getting James support at school in the following account:

> All through Grade 5, we were trying to work with the school and trying to get some sort of help for him. [Maybe a] teacher's aide. Finally, we just put our foot down and said “We have to get some testing for him. We have to get him help somehow.”

Gary and Carol, like Kevin and Leah, eventually took their requests for support to a higher level. They contacted the superintendant of the school board when they became frustrated with advocating for James at a lower level and felt like it wasn’t leading to the services they needed. They reported feeling like they had to “prod and push” to get support and resources, and do their own research to find out what options were available to them and to James, advocating each step of the way.

Outlook for the Future

The emotional impact of parenting a child with E/BD stretches into the future, into the hopes and fears that come with planning for the years ahead. Each of the parents interviewed expressed the same hopes that most parents have for their children: to finish school, to find a successful career, and to be happy. As Leah said of Adam, “I want him to thrive….I want him to be able to do whatever he wants to do.” The participants anticipated smaller hopeful steps for their children as well – the opportunity for re-integration into “regular classes,” progress in controlling their behaviour, joining activities with other children, and days without major difficulties at school.

Yet, their hopes were tempered with a great number of fears as well. Leah’s hope of Adam’s success was challenged by a fear that he will face failure in junior high school if he doesn’t get help earlier. This struggle with what will happen to their children once they leave the elementary years was common. Carol spoke of her worry that James won’t have the social skills to cope, and that it will affect him academically. Allison explained her concern that Ben will get into fights or be bullied. All of them expressed fear that their children may not be able to finish school, or may never be ready to move out of segregated special education classes.

As they looked towards the longer term, there were fears there too. Susan expressed anxiety over the idea that she may have to consider a group home or other facility for Adam because of his increasing violence. Allison described her fear that one day she will get a phone call from the police when Ben gets into trouble. The participants further articulated concerns that their children could be taken advantage of, be easily influenced by others, or get “involved with the wrong kind of people.” As Gary said, James is “definitely a follower not a leader right now.”

Gary and Carol also feared that James’ attention difficulty might impact his ability to stay at a job, and Gary went on to express his concern that James may always need a high level of support from them:

> It's tough. Some days you think you're always going to have to do something for him, right? You know, can he ever go out and live on his own? I don't know. It's

> hard right now to know if he's going to be okay or not. So I guess for now we just do whatever we can for him. And [hope] that he'll get more independent.

As educators and other providers consider services for children with E/BD and their families, the extent of the family impact becomes crucial. From the earliest signs of difficulty through to their hopes and fears about facing the future, the emotional and practical implications of parenting a child with E/BD are significant. Given the potentially far-reaching effects on parent stress, health, employment, and impact on other domains, families of children with E/BD might essentially be considered families in crisis. In this light, service delivery needs to extend beyond the needs of the child into areas of stress management, coping, education, and advocacy skills for parents. It also needs to take into account the reluctance of parents to seek help for themselves, and include ways to provide effective respite that families feel comfortable utilizing. Ultimately, it means that a level of sensitivity to and understanding of this pervasive impact needs to be considered in the planning and provision of all domains of care for children with E/BD and their families.

CHAPTER 6: NAVIGATING THE MAZES OF ASSESSMENT, DIAGNOSIS, AND MEDICATION

Assessment and diagnosis are some of the first processes that families of children with E/BD have to navigate when their child's behaviour begins to be recognized as problematic. For the participants in this study, assessment, diagnosis, and the consideration of medication were confusing and often overwhelming processes. Despite this, parents considered these as necessary steps towards beginning treatment and accessing service.

Assessment

The nature, purpose, and meaning of assessments seemed to be an area of particular confusion for the parents interviewed. Table 1 outlines the assessments that had been conducted for each child in and outside of school that were documented in each child's Student Record at the time of review. In addition, it appeared in the interviews for each case that there had also been additional assessments conducted that were not documented in Student Records, and were therefore not included in Table 1. When considering the number and range of assessments administered to each child, it is not surprising that the outcomes seemed confusing and overwhelming to parents. The youngest child, Ben, who also had the fewest assessments, had nine separate documented assessments conducted during his first two years of school. For each child, the bulk of assessments occurred during the one to two years immediately previous to or coinciding with his placement in a segregated special education classroom at school. The types of assessments documented included developmental, speech and language, occupational

Table 1

Assessments Completed for Each Child as Documented in Student Records

Case	Assessments conducted at school	Assessments conducted outside of school
Case 1 – Nathan		
Kindergarten Year 1	Speech and language Occupational therapy Cognitive	-
Kindergarten Year 2	Speech and language Physical therapy Cognitive Behavioural	Behavioural
Grade 1	Academic	-
Grade 2	Speech and language	-
Grade 3	Academic Cognitive Behavioural	-

Case	Assessments conducted at school	Assessments conducted outside of school
Case 2 – Adam		
Pre-Kindergarten	-	Speech and language
Kindergarten	-	-
Grade 1	Cognitive Behavioural Academic	Speech and language Occupational therapy Academic Psychiatric
Grade 2	-	-
Grade 3	Cognitive (pending) Behavioural (pending)	-

Case	Assessments conducted at school	Assessments conducted outside of school
Case 3 – Ben		
Kindergarten	Developmental screening Occupational therapy Cognitive Behavioural	Psychiatric
Grade 1	-	Academic Speech and language Occupational therapy Psychiatric
Grade 2	-	-

Case	Assessments conducted at school	Assessments conducted outside of school
Case 4 – James		
Kindergarten	-	Behavioural Psychiatric
Grade 1	-	Occupational Therapy
Grade 2	-	-
Grade 3	-	-
Grade 4	Academic Cognitive Behavioural Occupational Therapy	Occupational Therapy
Grade 5	Cognitive Academic Behavioural	-
Grade 6	-	-

Note: Dashes indicate that no assessments were documented for the year and location specified.

therapy, physical therapy, cognitive, behavioural, academic, and psychiatric assessments, representing a wide range of professionals with whom the families were communicating about the results.

The knowledge required to interpret results across all of these domains is expansive and it appeared that, in many cases, the families had little understanding of what the results of an assessment actually meant. Kevin described the outcomes of one assessment saying, “They were trying to see where he fit in, and it was all above average, average, less than average or something. Borderline. Something with learning curve or learning skills or whatever and he was borderline on everything.” Other parents gave similar descriptions that lacked the details to either convey what the assessments were measuring, or to determine any meaningful outcomes of the testing. The language or jargon used in assessment, rather than communicating meaningful information, appeared to have clearly impeded the parents’ understanding of the actual implications of the results.

The parents interviewed also expressed some confusion over whose responsibility it was to complete assessments, what the tests involved, and what the purposes were, demonstrated by Allison’s description that:

> …the school, like they did regular, as much as school can, testing, I’m guessing. I don't know exactly what the tests incur. I was just told what the results were. That was it. He was average here, below average here, above average here.

None of the parents gave a thorough, or even adequate, description of the assessments, demonstrating considerable lack of understanding about the kind of information contained in the child’s Student Records. For example, there were a number of assessments completed and documented in each child’s record that the parents appeared unaware of, or had forgotten about, when asked to describe the assessment history of their child during the interview process.

These experiences indicate that a communication breakdown can occur during the assessment phases, leaving parents inadequately informed about assessments and their outcomes. Where there has been a demonstrated lack of understanding regarding the meaning of assessment outcomes, it can be assumed that parents are therefore limited in their ability to use this information to make informed decisions, to advocate for services for their children, or to respond to the results and recommendations.

Diagnosis

Difficulties understanding the meaning of the assessments conducted for their children were reflected further in the parents’ lack of understanding of how these assessments led to diagnosis, and a generally minimal grasp of the connection between these processes. Two of the parental groups interviewed were unaware that their child had been given a specific diagnosis, or were aware of one diagnosis, but not of other diagnoses that had been assigned, even when these diagnoses had been documented in their child’s Student Record. This failure to understand the processes of assessment and diagnosis, and the connections between them, also appeared to contribute to feelings of confusion or mistrust of the involved professionals.

Some of this confusion resulted in part from the involvement of both medical and school professionals, who at times appeared in conflict. Prior to school, parents seemed to feel that they had limited expertise with which to determine whether the child’s behaviours were problematic, and thus relied upon their physicians’ advice, which, as previously mentioned, tended towards a reluctance to diagnose in early childhood. Later, when behaviours became problematic at school, parents appeared to be somewhat taken off guard and confused by the schools' reports of difficulty, given the earlier physician responses.

Once parents were aware that problematic behaviour existed at school, further confusion resulted from a lack of understanding about the connection between assessments and diagnoses. A common thread appeared in which each of the parents felt at some point that a given diagnosis was either inaccurate or unwarranted, and failed to understand how the diagnosis was achieved. Some parents felt that the person giving a diagnosis had only minimal information about the child before making this decision. Susan reported that she felt an ADHD diagnosis had been given because her son shuffled his feet, while Carol reported that an unwarranted diagnosis of Oppositional Defiant Disorder had been "fudged" in order to provide her son with segregated programming. In Leah's experience, she felt that a behavioural specialist visiting the home had suggested a possible diagnosis of Tourette's after just a few minutes with Nathan. All of the families reported some confusion over diagnosis, and it was common that parents reported that a diagnosis did not necessarily line up with their own experience with their child's symptoms. This experience was evident in Susan's account:

> Well originally [Adam] was diagnosed with just Tourette's. But I had been researching on my own and it just didn't sound right. Somebody had once told me when as a parent you go through this journey of kids with difficulties in learning and behaviours, trust your gut. And it just didn't sound right, and I said to [the psychiatrist] it sounds more like Asperger's, because some of the attention deficits

> that he had and the way he responded to things, the habits that he had were more of that.

Similarly, Allison reported that:

> [The psychiatrist] was quick to give Ben medication and to give him a diagnosis … Immediately he said it was Tourette's syndrome. I’ve read about Tourette's syndrome and Ben doesn't really have any of the symptoms that you get with it.

These instances suggest that parents need significantly more detailed information, particularly during the initial stages of collecting and sharing information regarding a child’s specific symptoms, in order to make meaningful connections between the process of assessment and the determination of a diagnosis. Doing so might also serve to alleviate the mistrust of both medical and education professionals that was inherent in these cases.

The process of diagnosis is made even more complex by the assignment of multiple diagnoses, and by the potential for the inconsistent presence of symptoms. In the cases studied, all of the children had at least two different diagnoses. Sometimes these different diagnoses were given by different professionals, and sometimes multiple diagnoses were arrived at by a single professional. Regardless, from a parental perspective, the presence of multiple diagnoses resulted in some confusion, especially when the symptoms of each diagnosis appeared to be in conflict. Carol expressed in the interview that:

> The thing I'm always struggling with is, [James] has opposing disorders, disabilities. Like … even though he can read very quickly, he doesn't necessarily comprehend everything right away, and he's very visual. And then he has another disorder that, I don't know… it's like almost contradictory.

Inconsistent symptoms further compounded the problem because at times, the symptoms shown by the child would appear to support one diagnosis, while parents reported that, at other times, they felt the symptoms better reflected a different diagnosis. Furthermore, symptoms appeared to increase or decrease over time, and some respondents wondered whether this indicated that a given diagnosis might no longer be applicable for their child. Clearly, the potential for diagnoses to both overlap in symptoms and to exist comorbidly needs to be communicated as part of the assessment and diagnostic processes. In addition, the non-static nature of symptoms should be discussed. Parents need to clearly understand what criteria a child meets as part of his or her diagnosis, and why this diagnosis was chosen over possible alternatives. As well, since behaviour almost certainly changes over time, particularly in early development, it is important that professionals and families alike continue to communicate and remain open to the possibility of reassessment and/or reconsideration of a diagnosis as symptoms change.

It should be noted that relatively easy access to information (and sometimes misinformation) about disorders through the internet and other media has complicated the role of the professional in communicating with families regarding the diagnosis and specific symptoms that a child exhibits. While there are many sources of reliable information available, it may be difficult for parents to discern how this information applies to their child. Some of the parents in the present study reported conducting their own research over the internet, and indicated that doing so led them to question the diagnosis of their child, given that some of the information they had gathered independently seemed to run counter to the diagnosis given by a professional. As such, part of the role of professionals involved in diagnosing behavioural disorders, in addition to the initial communication about the assessment of symptoms and diagnosis, will continue to be directing parents towards further reliable sources of information, as well as helping them to make sense of information they may gather independently.

Medication

After assessment and diagnosis, all of the parents interviewed pursued the possibility of medication as part of the treatment for their child's behavioural difficulties. All of the participants experienced some anxiety about this decision, and expressed that they felt reluctant to give their child medication and were wary of the potential side effects, but also felt that the severity of their child's difficulties warranted the use of medication. From the parents' perspective, the process of determining effective medications was just as, if not more, complex than the processes of assessment and diagnosis. All of the families tried more than one type of medication before feeling like it was successful, with one family deciding to stop medication altogether for several months when they didn't feel it was effective.

For all of the families, the anxiety they felt about the decision to give their children medication was centred on the issue of negative side effects. In particular, two parents mentioned their fear of giving their children medications considered "anti-psychotic". Despite their reluctance, each of the families proceeded with administering medication, acting on the suggestion of their child's doctor or psychiatrist. In Carol's words, "We don't like having him on a narcotic drug. Plain and simple. We'd rather not. But if it helps him to function, what choice do you have?"

All of the children involved in these cases were initially given stimulant medications, with parents reporting noticeable side effects. Kevin and Leah felt that while

Nathan was taking a particular stimulant medication, he was “a zombie”, and “either he was really high or he was really low… one or the other.” They eventually switched to giving Nathan a different stimulant medication, but at the time of the interview, didn’t feel this was effective anymore and were considering either increasing Nathan’s dosage, or changing his medication entirely. Susan felt the stimulant medication Adam started on was somewhat effective, but didn’t relieve some of his anxiety symptoms, so he also began taking an anti-anxiety medication. Both medications had to be increased shortly afterwards, and then the form of stimulant medication he took was changed, but Adam continued to experience the side effect of always feeling hungry. In Ben’s case, his initially prescribed stimulant medication was effective, but caused him to be unable to sleep. Other medications caused him to be increasingly aggressive, or too drowsy. His medications were changed at least five times before Allison felt they were working, and even then, Ben’s dosages were increased several more times to help make them more effective. James also experienced the side effects of altered eating and sleeping habits, and his dosage was continually increased until he had reached the maximum dosage, which still did not appear effective. This eventually led Gary and Carol to decide to cease giving James medication altogether for a period of time, but at the time of the interview, James had recently begun taking it again.

An additional source of frustration and anxiety about medication arose when parents felt that it was being prescribed too early, or when they felt that medication was being pursued as an isolated solution to their child’s problems. Susan expressed that Adam’s first medication was prescribed at his initial appointment with a psychiatrist, who she didn’t feel had fully investigated the problem. Susan wanted to know more about what Adam’s difficulties were before trying medication, and she didn’t feel that her concerns were heard. Similar frustration was heard from Carol and Gary as they explained that they felt that when they discussed James’ problems with staff at his school, “All the school wanted to talk about was drugs. That was frustrating.”

Just as with assessment and diagnosis, it is clear that successful treatment through medication must involve collaboration between professionals and families. Parents, as the people bearing the load of responsibility for their children’s well-being, sometimes undertook their own research into the medications suggested, inevitably heightening their concerns around administering them. As with the diagnostic process, medical professionals are likewise responsible for ensuring that parents are accurately informed about the benefits and side-effects of any medication prescribed, and for continuing to communicate about how these are manifested in a particular child’s case. Furthermore, this is a process during which parents continue to need support and information in order to minimize anxiety, increase their capacity to make informed decisions, and ensure that medications are considered as one part of a larger treatment plan.

The processes of assessment, diagnosis, and treatment through medication are not linear; they overlap and interact in ways which increase their complexity and add to the confusion sometimes experienced by parents. Additionally, as assessment, diagnosis, and medication may each be re-visited and therefore change over time, they are undoubtedly unique to each case. As such, the connections and interactions between them, as well as the specific implications for the individual child’s functioning, need to be communicated to parents on an ongoing and contextual basis in order to bring greater clarity and meaning to these processes.

CHAPTER 7: EXPERIENCES SEEKING SUPPORT AT SCHOOL

Many children with E/BD are initially identified through the school system. As such, schools might be considered a primary source of support and information for parents of children with E/BD. However, as the parents in this study described their experiences working with schools to access support for their children, the overwhelming theme was extremely high tension, beginning as early as the first communication about the child's difficulties, continuing through the assessment phase and into decisions surrounding classroom placement and the provision of services. During the interviews, parents conveyed a strong sense of mistrust, disagreement, and disillusionment with the supports their children received through their schools, particularly in the early phases of identification. These feelings are in line with those expressed in a similar study involving families of children with Tourette's Syndrome (Grace & Russell, 2005), in that most parents were dissatisfied with their attempts to receive support for their children through the school system and "generally feel in opposition to the school" (p. 51). Throughout the interviews for the present study, parents often used what Crawford and Simonoff (2003) identified as combative metaphors about battling or fighting to describe their attempts to access services. Some of this negative interaction appeared to abate with placement in a segregated special education classroom, but frustration about early school experiences lingered for all of the participants.

Identification and Assessment

For each of the families, tension between home and school began when their child started to display difficult behaviours at school. It was communicated very clearly that the parents interviewed did not feel like the school staff were working with them, but instead were working against them. In her interactions with Nathan’s Grade 1 teacher, Leah was left feeling “like [the teacher] just didn’t care.” Describing the school principal at the time, Leah said, “It’s weird because it’s almost like [he] didn’t believe me or something… It was really frustrating.” Gary and Carol expressed similar frustration with the support they were offered, explaining that they arranged to meet with James’ teacher and principal prior to him starting Grade 5, in order to talk about James’ needs and successful strategies for working with him. But Gary felt that when the school year started, “It seemed like then the kind of effort that they would've had to put forth to deal with [James] in a proper manner was too much for them. So they kind of just left it. And that’s when it started to go downhill.” Of the principal they were dealing with, Gary said “He was pretty tolerant of us, but… I always got the impression from him that he didn't really want to do anything.” Allison described her experience with Ben’s Grade 1 teacher by explaining that she was “quite disappointed in the fact that [the teacher] was pushing and pushing that something's wrong, something's wrong, something’s wrong.” But then, when Ben received support at a neurodevelopmental clinic outside of school, and staff at the clinic also offered support to the school, Allison was left with the impression that the teacher was not responsive to this support. Allison explained her emotional reaction to this, saying:

> I was kind of angry. I was just like “Okay well if you're the one who's saying there's a big problem here, why aren't you taking any help you can get to deal with him?” But [the teacher] didn't really seem that interested in it. So I was quite upset about that.

Susan also spoke of feeling “animosity” towards Adam’s first school, and particularly the school principal, as she explained that “instead of helping me, they just made it that much more stressful.”

One of the feelings that appeared to add to the tension experienced by families was a sense that the regular school wanted to get rid of the child, rather than support him in the current environment. For example, Susan felt she was supportive of the school’s efforts to have Adam assessed, and that she was willing to have him seen by a psychologist, talk about the results, and then decide what needed to be done. But she felt that the school had already decided that Adam didn’t belong there, because they called her three or four times a week to pick him up early from school, and because they had already conveyed that they wanted Adam to attend a segregated program. In Susan’s view, this felt like the school was saying to her, in her words, “We don't want to help you; we just want him out of here.” She felt she was fighting the school “every step of the way.” She described her relationship with the school, and what she felt she needed from them in this way:

> Work with me, as opposed to from day one, you were just trying to get me out of there, because you didn't like him. Like, I think a lot of the stress that was created, part of it was from him, but a greater part was from them because I was fighting them tooth and nail… I said “Let's just find out what we’re dealing with. Then after that, then we can figure out where to go.” But they just didn't want to wait.

Carol also felt that James’ school was just waiting for them to go elsewhere, and she experienced mounting frustration with the system. She voiced her thoughts, saying, “I don't know why they are willing to let them fall through the cracks. Because that's what it is exactly. It's just ‘Well sooner or later they'll be out of our hair.’”

The parents further articulated views that depicted schools as being oriented around the problem, rather than oriented around possible solutions. They described circumstances in which school staff would convey to them all of the difficulties experienced by the child at school, but offered no potential solutions. In addition, when they as parents attempted to offer solutions, they were left feeling that the school was unable or unwilling to implement them.

As such, the parents expressed that they felt much of the burden fell to them to advocate for their children in order to get service or assessment at school. In their study of parental perspectives, Grace and Russell (2005) stated that, “within this setting, parents feel the best interests of their child are not necessarily taken into account without active prompting” (p. 51). They also noted that of the participants in their study, “There was not a single parent who was unwilling to put large amounts of personal time and energy into working with the school.” (p. 55), and the same sentiments were found to be true of the parents interviewed for the present study. However, despite their willingness to collaborate, parents felt the process of getting support was slow, with assessment appointments booked months in advance, full assessments sometimes stretching over years, and as Allison said, “Nobody seemed concerned to get anything done.” While some of the parents conveyed that they were aware of the pressures a school might be facing in terms of budget, time, or resources, they also felt that the school wasn’t doing enough to be proactive, or at the very least that they as parents might not be receiving all of the information they would need to understand the school’s perspective. For example, Gary described their experience with trying to get support through the school in the following interview excerpt:

> We tried to work with the regular school last year… but we had to do all of the prompting. We had to do the advocating for him. Even though they knew he had issues and problems, they either weren't equipped to deal with it, or they didn't have the time, or they didn't want to put in the effort, right? So, we found that we had to do a lot. And we were willing to work with them but we had to prompt them.

Along with Gary and Carol, Kevin and Leah also felt that they had requested assessment and service for Nathan well before it actually occurred. Both of these families expressed frustration that the school had not heard their concerns and put supports in place earlier, and they were convinced that their children only eventually got service because they continued to press the school until support was provided. As Gary said, "Finally, we just put our foot down." After reaching an elevated level of frustration, Carol and Leah both took their concerns to the superintendant of the school district asking for help in order to be heard, and felt this aided them in getting their children assessed more quickly.

Leiter and Krauss (2004) explored the issue of parental requests for special education services and its relationship to satisfaction with the school in greater depth. Their results indicated that of parents who requested additional services related to their child's disability, 80% had difficulty obtaining the services. There were several problems noted by parents, including the inadequacy of available services, services being unavailable, difficulty finding the right service for the child, or lack of support from the school in assessing the child or providing access to service (Leiter & Krauss, 2004).

These difficulties in obtaining service led to much lower satisfaction with their child's education in general. Based on these results, Leiter and Krauss (2004) put forward that opportunities for collaboration between parents and school personnel in accessing appropriate services often have the potential to create conflict instead, a finding evidenced in the parental experiences shared in the present study.

Placement Decisions

Once assessment was completed, parents continued to feel that they lacked opportunities for cooperation with the school in terms of placement decisions. Two of the families felt they weren't presented with the option of special education support or a segregated classroom early enough. Gary and Carol conveyed that they weren't made aware that such classrooms existed, and felt that they found out only as a result of their own research into the available options. For them, the issue again centred on a lack of communication, with Carol stating that she felt, "You almost had to trick them into giving you information," both about the real difficulties James was experiencing, and about the possibilities for a special education placement.

After they found out such a placement was a possibility, Leah and Kevin wanted Nathan to be enrolled in a segregated special education program in order to receive supports, and pursued assessment for this purpose. But even after Nathan's assessment was complete, Leah reported that she had to phone the school in order to get the principal to look at the assessment documents that had been completed and tell her what was in them. It was then that she found out that Nathan had qualified for the special education program. During this conversation, the principal indicated that the transition would happen slowly, and that Kevin and Leah would be involved in a meeting to discuss the assessments. But the meeting never occurred, and within a week, Nathan was already placed full time in the segregated classroom. Even though this placement was what they had been seeking, their lack of involvement in the transition process was frustrating for Kevin and Leah.

Each of the other two families was made aware of the option of their child attending a segregated classroom very early on, but weren't initially sure that this was the right placement, and didn't feel that they were given any choice or involved in this decision. Susan recalled that Adam's school had suggested a segregated placement might be appropriate for him before he went into the neurodevelopmental assessment clinic, but no decision had been made. While Adam was still enrolled in the three-week assessment clinic, the community school he had been attending secured a place for him in a segregated program at a different school, effective upon his discharge from the clinic. Susan found out about the new placement from the assessment clinic doctor, and not from the school. She felt they had transferred Adam without her knowing, and was frustrated that this decision was made without her input. The school district where all of the families involved in this study were enrolled requires any school requesting a special education placement to state that the child's parents support the placement request. Despite this measure, it appears that placements are indeed sometimes made without the parents' full awareness.

Supports in Segregated Classrooms

At the time of interviewing, all of the child subjects of this study were placed in segregated special education classrooms for children diagnosed with Severe E/BD. In the school district involved, these classrooms typically have 7 to 12 students in them with two full-time staff – either two teachers, or a teacher and an educational assistant. The classrooms typically have students across three grade levels (in the cases studied, either Grades 1 through 3, or Grades 3 through 6), and operate as segregated programs within regular community schools. Because not all schools offer the program, designated sites are spread out across the city, and students are usually bussed to the nearest program to their home. As a result of the programs operating within community schools, some opportunities for students to be integrated in regular programming are available at the school's discretion.

Parents involved in the present study were asked to reflect on their child's segregated classroom placement, and whether they felt this placement was able to meet their child's needs. All of the parents stated that they felt their children were better supported in the segregated classrooms than they had been in regular classrooms. They tended to have better relationships with the teachers, with parents noting the openness, honesty and friendliness they experienced. Susan went so far as to say that "the teachers in this class have done a miraculous job with [Adam]." The participants also reported that their children received greater attention and enjoyed learning more, and that the smaller class sizes were helpful in achieving these outcomes. The parents of children with E/BD in Crawford and Simonoff's (2003) study described similar positive characteristics of segregated programming for their children.

Additionally, the parents in the present study felt that they were provided increased communication about their child's progress from the segregated classroom teachers. All of them received daily reports of their child's behaviour, which helped them to feel aware of what was happening at school. Susan described her satisfaction with this level of communication, saying:

> They've been really good with involving me and letting me know when he's done really, really good or if he's done something really inappropriate or what have you… She's really good at talking to me and touching base with me. And you know, if they have any concerns, she'll let me know.

While some conflict with the school was still reported after placement in segregated programming, it appeared that the increased communication and involvement allowed parents to resolve these conflicts with the school more quickly and amicably.

Despite their general overall satisfaction regarding the support received in segregated placements, some parents expressed concern that attention to academic achievement might be sacrificed by placement outside of the regular classroom, feeling that the focus of the segregated classrooms rested more on behavioural improvement. Kevin explained that the work Nathan was given when he was first placed in the segregated classroom was well below his capabilities, and made it seem that "it was almost like he went all the way back to Kindergarten." This made Kevin and Leah worry that Nathan would fall behind, and they brought their concerns to the classroom teacher. Although the teacher addressed them in part, at the time of the interview they continued to feel that the work at school was not challenging for Nathan, and feared that his academics might eventually be so delayed that he wouldn't be able to keep up if he was to return to a regular classroom. Regardless, they believed the segregated classroom continued to be the best placement for Nathan. Gary and Carol similarly believed that the segregated special education classroom was the best and most successful overall placement available for James, but in regards to academics, weren't convinced "that he's getting the best quality education he could."

General School Involvement

The general school involvement of parents of children with E/BD might be limited by a number of factors. One such factor is proximity to the school when a child is placed in a site other than the nearest neighbourhood school and takes a bus, limiting the amount of time a parent is physically present, when he or she might otherwise have accompanied his or her child to and from school. Another factor is the increased stress experienced by parents of children with E/BD which might limit their ability and/or willingness to take on additional commitments, including those at the school. However, even when they were willing and able, some parents in this study identified that their child's difficulties led to their exclusion from involvement in the school environment in unanticipated ways. For example, Allison had attempted to be part of the parent council associated with Ben's school. To participate, parents were asked to call ahead and state that they would be attending. Allison did so, but was later told that she couldn't go, because supervision wouldn't be available for Ben, even though it would be available for other children of parents attending the meeting. When she could not find outside childcare, she was unable to attend. Incidents such as this one that related to participation in the general school community, in addition to those specifically connected to their child's educational services, contributed towards the feelings of frustration and alienation experienced by the parents interviewed.

It is of particular note and concern that the parents involved in this study did not perceive schools to be a significant resource or source of help to them or their children.

When parents were asked where they would go to for help if they encountered further questions or concerns about their child's behaviour and needs, not one selected the school as a resource they would rely on. In fact, more than one specifically stated that they would intentionally choose not to ask the school, with Carol remarking, "That would be our last place to go for help."

CHAPTER 8: EXPERIENCES SEEKING SUPPORT OUTSIDE OF SCHOOL

In addition to the supports received through school, all of the families interviewed had sought out some type of support for their children and/or themselves from sources outside of the school. These included supports available through health care professionals, the government, agencies providing social services, and community groups. The type and range of supports sought and received through these sources varied, but when similar supports were accessed, parental experiences related to these supports also appeared similar.

Health Care Supports

The most common types of supports received outside of school were accessed through health care providers. Each of the families sought help from a family doctor or pediatrician in the early stages of their child's difficulties. Although as previously described, physician responses to the initial consultation varied, all of the children were eventually referred to additional mental health services through a neurodevelopmental clinic, a process facilitated by their physicians. Through these referrals, the families received services for their children from professionals specializing in mental health and E/BD.

The level of support received through this route varied. Nathan and James both received service as outpatients at the neurodevelopmental clinic, with minimal ongoing contact after an initial series of appointments in which medications were prescribed and adjusted. Nathan received a behavioural assessment at the clinic, and was referred to a mental health outreach program to continue as a resource for his parents, although it's unclear if or how much this program was later accessed. James was referred for further occupational therapy support.

The other two families, in contrast, received a substantially greater level of support and service for their children through the neurodevelopmental clinic. Both Adam and Ben attended an assessment classroom at the clinic, each first for a 3-week period. This was followed by a longer 12-week term in the assessment classroom for Adam, and an additional 3 and a half month full-time treatment period in a day program for Ben. As a result of being admitted to these programs, Adam and Ben both received many additional assessments and services in the areas of occupational therapy, speech therapy, social skills, and academics, as well as ongoing treatment from a psychiatrist assigned to their cases. At the time of the interviews, both Adam and Ben continued to have regular appointments to receive psychiatric care through the neurodevelopmental clinic. It is notable that Adam and Ben had more complex multiple diagnoses and appeared to have greater difficulty functioning at school than Nathan or James, likely contributing to the differing levels of clinical support received.

When asked to describe the people or services who had been most helpful to them, most of the parents chose health care professionals as having been the most supportive. Adam and Ben both received care through the same psychiatrist at the neurodevelopmental clinic, and their mothers clearly voiced that this psychiatrist in particular had been a significant and meaningful source of support for them. Elaborating upon the characteristics that made her an effective resource, Susan and Allison explained that they appreciated that she prescribed medication not in isolation, but as part of an overall treatment plan. She also discussed a variety of other potential treatment options with them, including things like natural dietary supplements, and made referrals for additional support in specific areas of need. In addition, both Susan and Allison felt that this psychiatrist had been direct and honest with them in discussing their children's difficulties, and that she helped them to better understand how a diagnosis was reached, as well as the complex nature of their children's specific symptoms. They further appreciated that the psychiatrist was available when they needed her, that she provided ongoing care, and that they felt they could go to her for help at any time and receive prompt service. Susan and Allison both responded without hesitation that the neurodevelopmental clinic of which this psychiatrist was a part had, as a whole, been a very significant source of support, and that many of the other health care professionals through this clinic had also acted as valuable resources. In particular, they appreciated the strong communication and sense of teamwork that had resulted from their interactions with the clinic.

Additionally, despite both positive and negative interactions recounted, all of the parents stated that their children's physicians had been helpful sources of support in the past, and would remain among the first resources to which they would turn if further supports were needed in the future. Clearly, medical professionals play a key role in both the assessment and treatment of children with E/BD, but also often function as both direct sources of information to caregivers and families, and as the link to additional services.

Government Supports

In the community where this study took place, a provincial government assistance program is in place to support families who have children with disabilities. Through this program, all families can access information about their child's disability, processes for referral, advocacy, and community programs. In addition, families can apply to receive financial assistance in caring for their child, including funds to access medical care, respite, and counselling. Direct services are also available, including aide support, assistance with child care, and other specialized services. All of the families in this study would have been eligible to apply for support through this program.

When questioned about their use of government services, only Susan and Allison had accessed these resources. Both James' and Nathan's parents had not only failed to access these services, but were completely unaware that such services existed, and had not previously considered the government as a potential source of support. This was true despite considerable information about the program available online, and may indicate a more widespread lack of awareness about these services among health and/or education professionals who could potentially serve as links to direct families to this resource.

When Susan and Allison were asked how they became aware of the government program, both replied that they seemed to have stumbled upon it in the course of seeking out other resources. Neither of them had intentionally sought out the government as a source of support, nor had been referred directly to it. Regardless, once they had accessed this resource, they both considered it to be an extremely helpful and valuable service. Both spoke highly of the government resource workers who served as their direct contacts with the program, and explained that the resource workers came out to their homes to meet with them, to establish what services could be provided, and to assist them in filling out the necessary paperwork. Following this inital meeting, the workers could be contacted directly to inquire about specific services the parents were seeking, and Susan and Allison viewed them as being reliable in returning phone calls quickly and following up with relevant information. Susan and Allison also appreciated that the government workers maintained ongoing contact with them to determine whether the current supports were sufficient and the child's needs were being met.

Given the anecdotal success of this government support for families of children with disabilities in Susan and Allison's cases, it is surprising that more of the parents interviewed were not previously aware of the program. However, it should be noted that it is unclear what role financial need plays in the provision of these services. Therefore, it is also unclear whether or not the other two families in this study, had they been aware of the services, would have received access to the same level of support as Susan and Allison had, given that Susan and Allison were functioning as single-parent and single-income households, whereas the other two households were dual-parent and dual-income. Nonetheless, even if financial support was not provided, the information and advocacy resources available through the government are accessible and potentially valuable to all families, and could therefore ideally serve as part of a wider plan for support.

Parenting Groups

The possibility of parenting groups serving as sources of support arose in all of the interviews conducted, despite the fact that it was not addressed directly in the interview questions. At the time of the interviews, no parents were currently participating in such groups. However, each of the parents had at one time been advised that a parenting group might be available, and all of them suggested that the idea of combining both peer and professional support was of interest to them, a sentiment echoed by the participants in another study of parental perspectives on E/BD (Crawford & Simonoff, 2003). Some of the potential benefits the participants in the present study could foresee included having a place to share struggles and successes, building a network of support, and being referred to additional resources.

It is interesting to note that some of the parents initially considered a referral to a parenting course to be somewhat offensive, likely at least partly because the suggestion seemed to infer that they as parents could or should do more to support their children. However, none of the parents fundamentally disagreed that their child's difficulties might at least partially be addressed through stronger parenting skills and strategies. It appeared that parents were not essentially opposed to strengthening their parenting skills or to the idea of attending groups that would help them to do so, but that the offense arose because they felt they were being offered this solution in the absence of other supports. Given these feelings, it is likely important that, as with any other course of treatment, the suggestion of parenting support groups be made by someone whom the family trusts, and that it be included as part of a well-rounded treatment plan.

Given that all of the parents agreed that support groups might be of interest to them, but that none of the parents were actually participating, several barriers to participation in support groups were brought forward by the interview participants. The most frequently mentioned barrier was time to attend. Leah explained that after working during the day, and exerting the extensive energy required to care for Nathan after he returned from school, she did not feel she would have the capacity to also attend meetings. All of the other mothers described similar scenarios.

Another common barrier was the inability to determine which parenting group would be most relevant for their needs. Both Susan and Allison explained that they were aware of parenting groups available for specific groups, for example for parents of children with Asperger’s Syndrome or Tourette’s Syndrome, but that their children did not fit any of the available groups accurately and therefore they weren’t sure if it would be of any value to them. Allison had even inquired about joining one, but the response she was given indicated that, despite her interest, she would not be permitted to participate because her son did not have a diagnosis that fit the defined criteria for the parenting group. She suggested that perhaps a parenting group simply for children that are difficult to handle might be able to meet the needs of parents of children with other disorders affecting their behaviour.

Finally, the issue of access also appeared to be a barrier to participation in parenting support groups. Through their responses, the parents interviewed explained that although parenting groups were proposed as a possible support, specific details about where or when these parenting groups occurred seemed to be lacking, and when information was given, the locations were not easily accessible. To address this difficulty, one parent suggested that perhaps this type of support could best be facilitated through schools, particularly where there are segregated classrooms of students who all exhibit behavioural difficulties, in which case it is likely that there are also groups of parents in need of support. Schools might also have the ability to provide specific information about support groups located closer to their students’ homes.

Other studies have explored the possibility of using parenting groups to address the needs of parents of children with E/BD and have suggested that the most effective groups minimize barriers by assisting with child care and transportation, and wherever possible, delivering the program within the community (Forehand & Kotchick, 2002). In addition, behavioural parent training may need to be accompanied by services to address other family problems, such as depression and stress (Forehand & Kotchick, 2002), given that variables such as maternal mental health can significantly impact the response to parent training (Reyno & McGrath, 2006).

Extracurricular Activities

All of the families identified extracurricular activities, such as sports, swimming, or summer camps, which they had either attempted or expressed desire to enrol their children in. James and Nathan had some successful experiences with involvement in these activities, while Adam and Ben had experienced less success with activities outside of school. Some of the benefits, strains and barriers associated with involvement were discussed.

The potential benefits of participation in extracurricular activities raised by the parents interviewed were similar to what might be expected for any child. Namely, the sense of belonging in a group and the opportunity for physical activity were identified as notable and desirable positive outcomes. However, these prospective outcomes were somewhat mitigated by fear of related negative outcomes, such as the possibility that their child might stand out significantly from their peers in the activity, and the increased chance that their child might act inappropriately or even aggressively in less-structured activities. Gary and Carol felt they had successfully enrolled James in a hockey team, but they perceived that this came at considerable sacrifice to them, as the time and effort it took to prepare James for participation and to organize his equipment seemed substantially greater than it might be for other children.

There were also other difficulties expressed that were associated with access to necessary supports in order to participate in activities outside of school. For example, Allison was aware that through his government support, Ben could receive some funding to pay for someone to accompany him to an activity, but she was unable to find anyone qualified and willing to do this. As she expressed:

> As parents, [we] have no idea what type of agency to go to. Or do I contact the school that they get taught at? Because I'd love for Ben to have an actual certified aide that could go to his soccer. They tell me I can pay a community aide to go and do these different activities. Those people would attend with him, and I'd be able to pay them ten dollars an hour when they go. But I have no idea where to find someone like that, [or even] a babysitter that has some type of training that would be able to actually have him go to bed at eight-thirty when he's supposed to and keep him on his routine.

The same was true for respite services Allison had tried to access to provide some care for Ben outside of school, and an opportunity for relief for Allison. Although the service was theoretically available, in practice she could not find a person or agency actually able to provide it. Susan encountered a different but related roadblock when she wanted Adam to participate in a summer camp, but was unable to find one willing to accept him or able to meet his needs. Similar findings of difficulty accessing out-of-school activities and appropriate child care by parents of children with E/BD were reported by Crawford and Simonoff (2003), who noted the contributions these difficulties made to parents' feelings of social exclusion and marginalization.

Other Sources of Support

Some of the families identified other sources of support that had played a significant role for them. Some of these sources were individual, such as friends who were willing to provide direct care for their children, or a daycare aide who had developed a long-term relationship with the family. Others were more widely available in their communities, which the parents engaged with either through seeking it out themselves, or through the recommendation of someone else. These sources of support included churches, independent agencies or charities for children with disabilities, and a recreation program for low-income families. Some of the parents expressed surprise that many of the services provided by these independent organizations, like access to recreation opportunities, had not been previously recommended through their contacts in education, health, or government support programs, and that they had to seek out these additional resources on their own. Of the families interviewed, the single mothers appeared to have engaged with a greater number of sources of support in their communities than the dual-parent families. In fact, neither of the dual-parent families was able to specifically identify any sources of support in their communities that they had accessed outside of education or health professionals. This may have resulted from a lower need for outside support, due to the fact that in dual-parent families the parents may act as strong sources of support for one another, greater availability of community resources to single-parent or lower-income families, or a combination of these and other factors.

A final striking finding from this portion of the interviews was that when parents were asked if they were aware of any sources of support which they had not yet accessed, all of the parents responded that they felt they had already tried to access everything that was available to them. They expressed that they knew there must be other supports available, but that they did not know how to go about finding them, and that when they had attempted to inquire about other resources on their own, they were met with frustration. It is clear that awareness of and accessibility to potential sources of support for families of children with E/BD remains an issue to be addressed.

CHAPTER 9: DISCUSSION ON DEFINING EFFECTIVE SUPPORT IN TERMS OF CONTINUITY, COMMUNICATION, AND COLLABORATION

When considering E/BD from a developmental perspective, individuals and their environment both contribute to the progression of disordered behaviour. The factors influencing behaviour are complex and interwoven, and impact development both directly and indirectly in ways that are unique to the individual (Wicks-Nelson & Israel, 2003). In this context, disordered behaviour is considered multi-faceted and dimensional, acting neither as a straight-line continuum, nor a construct that can be defined merely in terms of presence or absence. Rather, disordered behaviour develops over time, in relationship to the environment, and is defined in terms of deviation from normal development (Price & Lento, 2001).

As outlined in the review of relevant literature, many factors may either contribute to or counteract the probability of an individual developing disordered behaviour, and in a developmental perspective, these factors are often conceptualized in terms of their contributions to either risk or resilience in the child (Wicks-Nelson & Israel, 2003; Luthar & Prince, 2007). Characteristics contributing to risk and resilience may be either inherent to the individual or attributable to the environment, or an effect of the interaction between the individual and the environment. From an educational, health, or systems perspective, there is little control over many of the individual factors affecting disordered behaviour, including genetic predisposition, cognitive ability, and temperament. However, systems are able to exert some influence over many of the environmental factors that also play a role in the development of risk and resilience.

Many school and community factors have the potential to exert both direct and indirect influence on the functioning of the child over the course of development. But of all the environmental traits likely to affect a child's behaviour, familial factors are perhaps most critical for offering significant direct impact on a child. Given this, it is essential that risk and resilience be viewed not merely in terms of the child, but through the lens of the larger family context, and the supports provided to build resiliency in it.

This particular study focused on developing a better understanding of how school and community factors impact the child and family throughout the pre- and early school years, from the identification and assessment of individual characteristics, continuing through treatment and intervention. A summary of the findings is provided in Table 2. The intent was to consider these processes from the parental perspective, working under the assumption that resilience in children might be increased when systems are able to provide support that is meaningful to their families. A summary of the implications of these findings for educators and other professionals providing services to children with E/BD is presented in Table 3. In drawing together these implications, particular emphasis was placed on the supports that were perceived as desirable and effective to the parents interviewed, and the characteristics which made these supports meaningful. In addition, parents' expressions of frustration with or additional need for specific aspects of support were considered. Emerging from this holistic view of the findings was a clear and repeated focus on the concepts of continuity, collaboration, and communication as the essential elements of implementing effective supports.

Table 2

Key Findings – Parental Perspectives

Key findings derived from each area where parental perspectives on supports for children with E/BD were explored:

Early Signs & Family Impact

- Physicians appear reluctant to diagnose or refer children for assessment prior to beginning school.
- Having a child with E/BD impacts families in many ways, including: increased stress, feelings of guilt and blame, loss or reduction of employment, and increased advocacy roles.

Assessment, Diagnosis, and Medication

- The nature, purpose, and meaning of assessments can seem confusing to parents, particularly when a substantial number of assessments are conducted.
- Understanding how assessment leads or relates to a given diagnosis can be difficult, and is further complicated when multiple diagnoses are given over time or comorbidly.
- Decisions to pursue medications to treat symptoms of E/BD, and the perceived side effects of these medications, are a source of anxiety for parents.

Experiences Seeking Support at School

- Relationships between schools and parents of children with E/BD are often strained, with parents feeling like school personnel are working against them and that the burden falls to them as parents to advocate for service at school.
- Placement decisions are sometimes made without parents’ full participation or awareness of their options.
- Parents of children with E/BD in segregated programming generally express positive feelings about this placement, particularly related to the additional supports provided in this setting.

Experiences Seeking Support Outside of School

- The most common types of supports received outside of school are those accessed through health care providers, who are generally considered to be positive and helpful sources.
- Although government supports are viewed as strongly beneficial by those who access them, general awareness of the availability of these supports may be low.
- Parenting groups are seen as potential sources of meaningful support, but several barriers exist that may hinder actual participation.
- Opportunities for children with E/BD to participate in extra-curricular activities or typical child-care settings are perceived as limited.

Table 3

Key Findings – Implications for Schools and other Service Providers

Implications of the key findings for schools and other service providers include:

Early Signs & Family Impact

- Schools are often the first source of information about a child's mental health and behavioural difficulties.
- Parents of children with E/BD are under significant strain and may be in need of supports not just for the child, but for themselves.

Assessment, Diagnosis, and Medication

- Information about assessments needs to be clearly communicated to parents in language that emphasizes the implications for their child's functioning at home and school.
- Relationships between assessments and a given diagnosis should be communicated as part of the assessment process.
- Administration of medication must be considered as one part of a holistic treatment plan, with support given to families to make informed decisions.

Providing Support through Schools

- Relationships between schools and parents of children with E/BD can be strengthened through open communication and collaboration that emphasizes the value of the parental role.
- Parents' full participation in placement decisions should be encouraged and supported by creating awareness of placement options.
- Consideration should be given to the processes through which the perceived benefits of segregated settings for children with E/BD might also be incorporated into less-restrictive settings.

Providing Support Outside of Schools

- Collaboration and communication between schools and health care providers is necessary to ensure continuity in service.
- Parental awareness of the availability of government supports might be improved by increased distribution of this information through schools and other service providers.
- Barriers to participation in parenting groups must be minimized in order to yield the potential benefits of this support for children and families. Partnerships with schools might be considered as a possible means to address this need.
- Improved support systems that would enable children with E/BD to participate in extra-curricular activities or typical child-care settings are needed.

Continuity

A lack of continuity between services was evident in each of the cases presented. Information from assessments conducted through services outside of the school was often not documented in school files, and likewise parents appeared to be unaware of much of the educational and assessment information contained in their child’s Student Record at school. As a result, some assessments were repeated by different sources within short amounts of time, and information about the child’s diagnostic history provided either by the child’s parents or by the school was often fragmented and incomplete. Likewise, individuals who were perceived to facilitate continuity between services were seen as helpful and meaningful sources of support for parents.

Other studies have also stressed the need for increased communication between services in order to share information (Crawford and Simonoff, 2003) and ensure continuity. At present, services often rely on parents to communicate information to other relevant professionals, but it is apparent that consideration also needs to be given to the parents’ ability to effectively relay large amounts of information that may contain high-level assessment and diagnostic vocabulary. Given that the parents in this study were unable to meaningfully describe to the researcher the results of any assessments, it is unreasonable to assume that they could bear the responsibility to communicate this information to other relevant professionals. Although confidentiality is often stated as a reason for the reliance upon parents to convey this information between service providers, none of the participants in Crawford and Simonoff’s (2003) study, nor in this one, cited confidentiality as a concern when services shared information. As such, policy changes that support the sharing of relevant information may be necessary to pave the way for increased continuity between services in and outside of school.

A potential benefit of shared information and more effective continuity between service providers is that it might serve to reduce the duplication of services that often occurred, and likely contributed to the seemingly slow process parents encountered when attempting to access assessments and supports. Although parents had sought help early, none received services before their child began school. Other studies have noted that although parents tend to be aware of behavioural difficulties in the preschool or very early years, a two-year gap exists between the time parents report their child's behavioural difficulties and their actual access to services (Rosenzweig, Brennan, Huffstutter, & Bradley, 2008). Based on evidence that parents and medical professionals could quite accurately identify the presence of behaviour problems in children by age 4 that later persisted into the school years, Fanton, MacDonald, and Harvey (2008) suggest that "there is a critical need for more research to develop appropriate early treatments for this population" (p. 481), and encourage early referral in these cases. Barnett et al. (2006) propose that early use of response to intervention (RTI) techniques for children with challenging behaviours may be part of developing a system in which needs are identified earlier and supports put in place as young as the preschool years in order to build resiliency and lessen the time before service is received. In Barnett et al.'s (2006) ideal, these supports would include transition services to minimize challenges for these children as they enter school, and doing so would ensure greater continuity. However, they admit that more work to develop effective screening tools and intervention strategies for young children with challenging behaviours is necessary before RTI can be successfully used or monitored in these cases (Barnett et al.).

In addition to a lack of continuity between services, a lack of continuity in staff within a given service was also persistent and noted by parents in the present study, causing delays in service and breakdowns in communication, and sometimes leaving parents without knowledge of who to contact for support after a given contact was no longer employed. Crawford and Simonoff (2003) noted that changes in staff were a problem across all services identified in their study, but were particularly prevalent relative to health services. The participants in the present study identified that this was also an issue with school staff, and with government workers assigned to help them access supports. Parents expressed the need for contact with somebody who understood the full picture of their child's needs and the services available to support them.

Collaboration

Throughout the interviews, the participants stressed their willingness to work together with teachers and other professionals, and their desire to establish a sense of teamwork and collaborative problem-solving. The results of Grace and Russell's (2005) study of parental perspectives regarding children with Tourette's syndrome suggested an ideal that would involve the regular engagement of parents, children, and teachers in discussions about the child's needs, concerns, and strategies to provide support. Given that no two children or families will present with identical needs, and therefore the accommodations required to meet these needs will also vary, flexibility and responsiveness on the part of the school remains key to the development of successful collaboration (Grace & Russell, 2005).

Based on a study of parents' requests for and difficulties obtaining special education services, Leiter and Krauss (2004) support the idea that there is room for improvement in parent-professional collaboration within schools. They propose that in order to facilitate collaboration, systems for providing knowledge about special education services to both parents and professionals need to be strengthened, such that all participants are aware of the available services and their roles in accessing them. However, they also identified some barriers to this collaboration, particularly the constraints that schools face in terms of personnel and funding that place limits on the services a school is able to provide (Leiter & Krauss, 2004). Since opportunities for collaboration will always exist within the frameworks of both policy and finance, these environments in themselves may contribute to either conflict or collaboration between parents and professionals in providing for a child's needs. Given these limitations, open communication from schools about the services they are and are not able to provide, and building the capacity for schools to refer parents to services that might be accessed outside of school remain critical components of fostering collaboration and maintaining positive parent-professional relationships.

In addition to the barriers of financial resources and policy, others identify teachers' limited training in conferencing with parents, the imbalance of power in meetings, and differing perspectives between parents and educators as barriers to positive school-parent relationships (Nietsch, Siegel, Keefe & Horne, 2008). In order to overcome these barriers and foster collaboration, ongoing skill development and support is needed for both parents and educators of children with E/BD. To achieve this aim, Cheney, Osher, and Caeser (2002) suggest that "an emphasis must be placed on building the capacity of educational staff to teach and work effectively" (p.80). In order to strengthen this capacity, parents and educators must have common goals, must be supported by administrators, and must be provided with opportunities for professional development to enhance their knowledge and skills (Cheney et al., 2002). Furthermore, the isolation of school staff must be decreased so that teams of professionals within schools work together to support students with challenging behaviour, perhaps through the creation of specific behaviour support teams who work together to identify needs and potential strategies to improve success (Cheney et al., 2002).

Others have suggested that collaboration might also be fostered between schools and parents of children with E/BD through the use of innovative projects like participatory action research (PAR) (Ditrano & Silverstein, 2006), in which parents are encouraged to tell their own stories, collectively develop awareness about special education, and plan projects which enable them to act on behalf of their children. Ditrano & Silverstein's (2006) work demonstrated that participating in a project like this provided social support for the families, generated optimism, and created a sense of empowerment. They also speculated, based on later evidence of student placements, that this information helped the school to better understand the parents' needs and to respond. While PAR may not be feasible in many circumstances, the basic principles of listening to individual parental experiences, sharing knowledge, and encouraging active collaboration from parents remain relevant in any setting.

Communication

For the parents interviewed, circumstances in which they experienced frustration almost always centred around issues of communication. So too did their experiences of positive relationships with professionals, with many conflicts being resolved easily once more effective communication was established. Parents expressed a desire for school personnel to be honest and straightforward with them, even if the message to be communicated was inherently negative. They spoke of their appreciation of openness and transparency about the real needs of their children and the supports available to meet them. They communicated the value they placed on professional opinions, and at the same time expressed their desire to be heard. Crawford and Simonoff (2003) identified that for parents of children with E/BD, reciprocity is an important component of developing effective communication with professionals. That is, parents value a relationship that is interactive, that considers their ideas equally, and that works to develop a shared perspective (Crawford & Simonoff, 2003). In contrast, communication and effective relationship-building is hindered by experiences of authoritarianism, empty promises, the denigration of other professionals, and a lack of training on the part of school staff (Crawford & Simonoff, 2003).

An important aspect of the communication between schools and families involves the creation of the Individual Education or Program Plan (IEP or IPP) for the child. This document is intended to capture the needs and strengths of the child, as well as facilitate goal-setting and monitoring of progress. Used effectively, it can be an important communication tool to engage schools and families in collaborative thinking and planning. In the cases involved in this study, it was interesting to note that Student Records sometimes contained incomplete IEP/IPPs, and in one case no IEP/IPP was available at all. In revisiting a school’s capacity to communicate with parents, these documents would ideally serve as a focusing point and a basis for collaborative meetings.

In a study of parental perceptions of IEP/IPP meetings, most respondents held positive perceptions of these meetings, and were left with the sense that educators valued parental input and treated them with respect (Fish, 2008). Fostering collaboration through these meetings can be as simple as creating a welcoming atmosphere, using the time to build relationships with families, using familiar language, and allowing parents to be active participants (Fish, 2008).

As schools and communities strive to reach these ideals, it may be necessary to re-envision a system in which someone holds the specific role and responsibility of facilitating this continuity, collaboration, and communication between professionals and families. One possibility is that this role could be held by a caseworker or coordinator who has ongoing contact with the family and all professionals involved (Crawford & Simonoff, 2003). Others have suggested that this might be a role best played by a school psychologist (Grace and Russell, 2005). Barnett et al. (2006) suggest that the role of school psychologists may see considerable change as schools shift their focus towards intervention services, but agree that school psychologists may indeed be best poised to be effective leaders in planning, prevention, problem solving, and decision making in schools serving children with E/BD.

Study Limitations

Typical of many studies involving participants from marginalized groups, this study involved a small sample size, and therefore does not indicate the prevalence of the views expressed. While the small sample size allowed for in-depth exploration of parental experiences, it does not hold the power to suggest that these views are representative of a larger population, and as such, the results should be interpreted with caution.

Additionally, participants were recruited via information distributed through their child's school. They were self-selected by volunteering their participation, and because of this, may over-represent a sample of parents who are quite active in their child's education, or may otherwise be a group with atypical characteristics. Furthermore, their views were collected at a time when their children were already placed in segregated special education settings for children with E/BD, and may be different from those they would have expressed had their children been placed in a different setting, or if they were interviewed prior to this placement.

Areas for Further Research

Further research in several areas could contribute to the practical application of the perspectives presented. First, the experiences of teachers in meeting the needs of children with E/BD and their families should be explored in order to gain a more holistic view of systematic successes and challenges. Considering the perspectives of other service providers, including mental health professionals, would likewise contribute valuable and needed information.

Further research with larger groups of parents is needed to explore the prevalence of the concerns and successes participants expressed in this study in order to determine the relevance and generalizability of the results to larger groups. In addition, information about how family characteristics such as socio-economic status or family structure relate to parental experiences of support is needed.

Lastly, examination of strategies that have been successful in building collaborative relationships with parents of children with disabilities other than E/BD might be used to expand upon the results and develop steps towards the practical implementation of the recommendations made.

Concluding Thoughts

There are many effective things that schools and other professionals are already doing to successfully meet the needs of children with E/BD and their families. Yet, there is also certainly a large amount of room for improvement in the provision of service, which must be built on the basic principles of ensuring continuity, collaboration, and communication. Allison perhaps best summarized parental perspectives on the supports available when she said:

> I don't believe that it's all wrong. But yes, just like in every other system, there are problems. There [are] little things that need to be fixed. But [they can't be] if nobody notices that there's a problem or that things need to be fixed. Like fine things just tweaked a little bit could make things so much easier for everybody involved…and that would be great.

And just as articulately, Allison spoke of her ultimate hopes for Ben, like the hopes of so many parents for their children, with E/BD, or without:

> I don't want him to suffer because of [his disorder]. I would like him to be able to finish out school and attend junior high and high school and college, and get a good education and a diploma and say 'Yay, look mom!' – without having to suffer through it.

REFERENCES

Barnett, D., Elliott, N, Wolsing, L, Bunger, C., Haski, H., McKissick, C., et al. (2006). Response to intervention for young children with extremely challenging behaviours: What it might look like. *School Psychology Review, 35*(4), 568-582.

Blader, J. C., & Jensen, P. S. (2007). Aggression in children: An integrative approach. In A. Martin & F. R. Volkmar (Eds.), *Lewis's child and adolescent psychiatry: A comprehensive textbook* (4th ed., pp. 467-483).

Brennan, A., & Heflinger, C. (1997). The caregiver strain questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. *Journal of Emotional & Behavioral Disorders, 5*(4), 212-222.

Brennan, E. M., & Brannan, A. (2005). Participation in the paid labor force by caregivers of children with emotional and behavioral disorders. *Journal of Emotional & Behavioral Disorders, 13*(4), 237-246.

Chassin, L., & Ritter, J. (2001). Vulnerability to substance use disorders in childhood and adolescence. In R. Ingram & J. M. Price (Eds.), *Vulnerability to psychopathology: Risk across the lifespan* (pp. 107-125).

Cheney, D., Osher, T, & Caesar, M. (2002). Providing ongoing skill development and support for educators and parents of students with emotional and behavioural disabilities. *Journal of Child and Family Studies, 11*(1), 79-89.

Crawford, T., & Simonoff, E. (2003). Parental views about services for children attending schools for the emotionally and behaviourally disturbed (EBD): A qualitative analysis. *Child Care, Health & Development, 29*(6), 481-491.

Cresswell, J. W. (2005). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (2nd ed.). New Jersey: Pearson Merrill Prentice-Hall.

Dodge, K. A. (2003). Do social information-processing patterns mediate aggressive behavior? In B. Lahey, T. Moffitt, & A. Caspi (Eds.), *Causes of conduct disorder and juvenile delinquency* (pp. 254-271).

Douma, J. C. H., Dekker, M. C., & Koot, H. M. (2006). Supporting parents of youths with intellectual disabilities and psychopathology. *Journal of Intellectual Disability Research, 50*(8), 570-581.

Ditrano, C. & Silverstein, L. B. (2006). Listening to parents' voices: Participatory action research in the schools. *Professional Psychology, Research and Practice, 37*(4), 359-366.

Fanton, J. H., MacDonald, B., Harvey, E. A. (2008). Preschool parent-pediatrician consultations and predictive referral patterns for problematic behaviors. *Journal of Developmental & Behavioral Pediatrics, 29*(6), 475-482.

Farmer, T. W., Quinn, M. M., Hussey, W., & Holahan, T. (2001). The development of disruptive behavioral disorders and correlated constraints: Implications for intervention. *Behavioral Disorders, 26*(2), 117-131.

Farrington, D. P., & Welsh, B. C. (2004). Prevention and early detection of conduct disorder and delinquency. In Remschmidt, Belfer, & Goodyer (Eds.), *Facilitating pathways* (pp. 287-298).

Fish, W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure, 53*(1), 8-14.

Flyvbjerg, B. (2006). Five misunderstandings about case-study research. *Qualitative Inquiry*, 12(2), 219-245.

Forness, S. R., & Kavale, K. A. (2000). Emotional or behavioral disorders: Background and current status of the E/BD terminology and definition. *Behavioral Disorders, 25*(3), 264-269.

Forehand, R., & Kotchick, B. A., (2002). Behavioral parent training: Current challenges and potential solutions. *Journal of Child and Family Studies, 11*(4), 377-384.

Gartstein, M. A. & Sheeber, L. (2004). Child behavior problems and maternal symptoms of depression: A mediational model. *Journal of Child and Adolescent Psychiatric Nursing, 17*(4), 141-150.

Goldstein, L. H., Harvey, E. A., & Friedman-Weieneth, J. L. (2007). Examining subtypes of behavior problems among 3-year-old children, part III: Investigating differences in parenting practices and parenting stress. *Journal of Abnormal Child Psychology, 35*(1), 125-136.

Grace, R. & Russell, C. (2005). Tourette's Syndrome and the school experience: A qualitative study of children's and parents' perspectives. *Australasian Journal of Special Education, 29*(1), 40-59.

Harvey, M. T., Lewis-Palmer, T. Horner, R. H., & Sugai, G. (2003). Trans-situational interventions: Generalization of behavior support across school and home environments. *Behavioral Disorders, 28*(3), 299-312.

Keisner, J., Dishion, T. J., & Poulin, F. (2001). A reinforcement model of conduct problems in children and adolescents: advances in theory and intervention. In Hill

& Maughan (Eds.), *Conduct disorders in childhood and adolescence* (pp. 264-284).

Lahey, B. B., & Waldman, I.D. (2003). A developmental propensity model of the origins of conduct problems during childhood and adolescence. In B. Lahey, T. Moffitt, & A. Caspi (Eds.), *Causes of conduct disorder and juvenile delinquency* (pp. 76-105).

Luthar, S. S., & Prince, R. P. (2007). Developmental psychopathology. In A. Martin & F. R. Volkmar (Eds.), *Lewis's child and adolescent psychiatry: A comprehensive textbook* (4th ed., pp. 291-299).

Leiter, V. & Krauss, M. (2004). Claims, barriers, and satisfaction: Parents' requests for additional special education services. *Journal of Disability Policy Studies, 15*(3), 135-146).

Marcus, R. F. (2007). Developmental pathways to violence (Chapter 2). In *Aggression and violence in adolescents* (pp. 35-54).

Marcus, R. F. (2007). Personality risk factors for aggression and violence (Chapter 3). In *Aggression and violence in adolescents* (pp. 55-79).

Marcus, R. F. (2007). Situational risk factors for aggression and violence (Chapter 4). In *Aggression and violence in adolescents* (pp. 80-107).

McGill, P., Papachristoforou, E., & Cooper, V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behaviour. *Child Care, Health & Development, 32*(2), 159-165.

Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco: Jossey-Bass Publishers.

Moffitt, T. E. (2003). Life-course-persistent and adolescence-limited antisocial behavior: A 10-year research review and a research agenda. In B. Lahey, T. Moffitt, & A. Caspi (Eds.), *Causes of conduct disorder and juvenile delinquency* (pp. 49-75).

Nietsch, P., Siegel, C., Keefe, C., & Horn, K. (2008). Partnering with parents of special needs students: Barriers to collaboration. *Communiqué: The Newspaper of the National Association of School Psychologists, 37*(1), 1, 16-19.

Nock, M. K., Ferriter, C., & Holmberg, E. (2007). Parent beliefs about treatment credibility and effectiveness: Assessment and relation to subsequent treatment participation. *Journal of Child and Family Studies, 16*(1), 27-38.

Pettit, G. S., Polaha, J. A., & Mize, J. (2001). Perceptual and attributional processes in aggression and conduct problems. In Hill & Maughan (Eds.), *Conduct disorders in childhood and adolescence* (pp. 292-315).

Price, J. M., & Lento, J. (2001). The nature of child and adolescent vulnerability: History and definitions. In R. Ingram & J. M. Price (Eds.), *Vulnerability to psychopathology: Risk across the lifespan* (pp. 20-35).

Pugach, M. C. (2001). The stories we choose to tell: fulfilling the promise of qualitative research for special education. *Exceptional Children, 67*(4), 439-453.

Rey, J. M., Walter, G., & Soutullo, C.A. (2007). Oppositional defiant and conduct disorders. In A. Martin & F. R. Volkmar (Eds.), *Lewis's child and adolescent psychiatry: A comprehensive textbook* (4th ed., pp. 454-466).

Reyno, S. M., & McGrath, P. J. (2006). Predictors of parent training efficacy for child externalizing behaviour problems – a meta-analytic review. *Journal of Child Psychology and Psychiatry, 27*(1), 99-111.

Rosenzweig, J. M., Brennan, E. M., Huffstutter, K., & Bradley, J. R. (2008). Child care and employed parents of children with emotional or behavioral disorders. *Journal of Emotional and Behavioral Disorders, 16*(2), 78-89.

Rosenzweig, J. M., Brennan, E. M., & Ogilvie, A. M. (2002). Work-family fit: Voices of parents of children with emotional and behavioral disorders. *Social Work, 47*(4), 415-424.

Ross, C. N., & Blanc, H. M. (1998). Parenting stress in mothers of young children with oppositional defiant disorder and other severe behavior problems. *Child Study Journal, 28*(2), 93-110.

Tremblay, R.E., & Nagin, D.S. (2005). The developmental origins of physical aggression in humans. In R. Tremblay, W. Hartup, & J. Archer (Eds.), *Developmental origins of aggression* (pp. 83-106).

Trembley, R. F. (2003). Why socialization fails: The case of chronic physical aggression. In B. Lahey, T. Moffitt, & A. Caspi (Eds.), *Causes of conduct disorder and juvenile delinquency* (pp. 182-214).

Wicks-Nelson, R. & Israel, A.C. (2003). Disordered behavior: The developmental psychopathology perspective. In *Behavior Disorders of Childhood* (pp. 21-39).

APPENDIX
Semi-Structured Interview Guide

Family-focused

1. Describe your child and your family.
    a. How many children are there?
    b. How old are the children?
    c. What is the parenting structure in the family?

2. Describe your child's behaviour difficulties.

3. When did you realize or begin to understand that your child had behaviour difficulties?

4. How did your child get his/her diagnosis?
    a. Who gave your child this diagnosis?
    b. When was your child diagnosed?
    c. Do you understand the diagnosis?

5. How did you react when your child was first diagnosed?

6. Did you ask anyone for help?
    a. Who did you ask for help first?
    b. When did you start asking for help?

7. How do you think your child's disorder has affected your family? You as a parent?

8. What would you say have been your greatest challenges parenting your child?

9. As you look to the future for your child, what do you anticipate to be struggles or successes? What do you think that looks like?

School-focused

10. Did your child receive help before school (early intervention)?
    a. From who?
    b. How did you get this help?
    c. Do you think it was a successful experience?

11. Describe your child's experiences at school.
    a. What kind of programming or support does your child receive at school?
    b. What successes or challenges has your child faced at school?
    c. How does your child do academically?

12. Describe your experiences accessing school supports for your child.
    a. Did you anticipate any challenges for your child at school?
    b. What was the school's response to your child's difficulties?
    c. Was your child tested at school? For behaviour? For academics? What communication did you receive about this?
    d. How involved have you been with the programming decisions made for your child at school?
    e. What successes and challenges have you found in your interactions with the school?
    f. Do you feel your child is getting the support he/she needs at school?

13. Is there anything you think the school could have done better or differently to support you or your child?

Community-focused

14. Have you tried to get support for you or your child through the community or other agencies?
    a. Where have you tried to get support from?
    b. How did you try to get support?
    c. Were you successful in getting support this way?
    d. Was there a cost to you?

15. What community services or other agencies have you accessed for assistance?
    a. How often?
    b. What did/do they provide?
    c. How did you hear about them?

16. What involvement do you have with other professionals (family doctor, psychologist, mental health services, etc.)? How did you access these professionals? What kind of support do they give you?

17. Have you applied for any support through the government?

18. Do you know about other services or agencies in your community that provide support that you have not accessed?

General Support

19. Is your child on medication? How did this come about? What have been your experiences (fears, successes, challenges) with it?
20. Who do you feel has been the most helpful to you in supporting you and your child?

21. What successes or struggles have you faced when trying to get help?
22. Has there been anything that stopped you from asking for help when you needed it?
23. Do you feel like you know where to ask for help if you need it now?
24. Are there any services that you wish had been provided by your school or community that you haven't found?
25. What kind of supports do you think you might need in the future?
26. Is there anything else that you think is important to include to understand your experiences?