

**Parents' Perceptions of Acceptability of Medication to Treat Emotional Behavioral
Disorders in Children**

by

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ABSTRACT

Emotional Behavioral Disorder (EBD) is a term used within the educational system to describe those students who in spite of supports for their emotional and behavioral difficulties, continue to struggle academically and negatively impact their peers. Children with EBD are one of the most difficult segments of the education population to integrate into the regular classroom due to their disruptiveness and the individuality of their needs. Strategies that have been used to help children with EBD include those with a cognitive and/or behavioral focus (both individually or in the classroom setting), those aimed at improving parenting skills and those that use prescription medication either by itself or as an adjunct to more behaviorally oriented treatments.

In spite of increased usage and proven efficacy, however, many parents are reluctant to consider medication as a treatment alternative, and those who opt to use medication perceive their child stigmatized in their educational experience. The purpose of this qualitative study is to explore parental perceptions of medication use to address Emotional Behavioral Disorders and their satisfaction with using medication to address school based difficulties. Using grounded theory methodology, in depth, open-ended interviews with seven mothers of students identified as EBD were used to obtain information about their experiences and perceptions. Interviews were analyzed using a constant comparative method. The findings suggest that parents' decision to use medication to address a child's behavioral difficulties were based primarily on their own history of medication use and their relationship with school personnel. Implications and recommendations for school personnel and planning are then summarized.

CHAPTER 1

Introduction

Emotional Behavioral Disorder (EBD) is a term used specifically within the educational system to identify those students who have ongoing difficulties in the emotional behavioral realm. In Canada, the definition of EBD varies across provinces. As such, so do the rates of prevalence. Smith et al. (2006) suggest that up to 19% of children in Canadian schools are at risk of poor outcomes due to behavioral problems.

One way to conceptualize EBD in the education system is to envision a continuum, where behaviors on either extreme are considered dysfunctional. Specifically, one extreme is internalizing (behaviors directed inwards) and the opposite externalizing (behaviors directed outwards). “Disordered” functioning, then, is one extreme or the other. *Externalizing behaviors* include aggression, temper tantrums, lying and stealing, argumentativeness, and lack of self-control. *Internalizing behaviors* include withdrawal and avoidance, fearfulness and anxiety, sadness or depression, oversensitivity, and irritability (Smith et al., 2006). One definition suggests that students with EBD are those who in spite of receiving supportive educational and social emotional services, continue to evidence difficulties that interfere with their own and others’ learning. “The inability of these students to achieve adequate academic progress and satisfactory interpersonal relationships cannot be attributed to physical, sensory or intellectual deficits” (Algozzine cited in Smith et al., p.147).

There is disagreement between disciplines responsible for mental health care regarding the usefulness of the EBD label. For psychologists and psychiatrists, the term is vague and the specificity of a diagnosis from the *Diagnostic and Statistical Manual of*

Mental Disorders- IV-TR (APA, 2000) is preferred because it differentiates disorders typically categorized as EBD into specific diagnosable mental illnesses; the etiology of which are more readily determined. The reality is that for educational purposes, children are placed in the EBD category so that their academic planning can be delineated and specialized according to their needs. The difference between how the education and medical professions conceptualize EBD can be characterized as diagnostic versus dimensional. Mental health professionals who utilize the diagnostic approach determine if an individual meets diagnostic criteria. Within the educational system, however, a dimensional or continuum approach is utilized so that children can have varying degrees of Emotional Behavioral Disorders or displays of severe behavior in school settings without necessarily having a medical diagnosis.

Many children who have been given the EBD designation in schools respond well to environmental adjustments and adaptations to their educational programs. Other groups of children labeled EBD require more intensive supports in order to manage academic and social demands (Manitoba Education, Citizenship and Youth, 2001). When children with EBD require increased supports in the classroom or school setting, schools must request additional funding support. The funding guidelines implemented by the provincial department of education not only ensure conformity to a definition of EBD they also ensure homogeneity in the level - though not the kind of support - provided to the child. This provides an operational definition of EBD in Manitoba and outlines the amount of money an individual child so affected will be given to have their programming delivered in Manitoba.

The provincial department of education has categorized funding support into levels, which denote the severity of the Emotional Behavioral Disorder, the child's needs, and the funding amount that the school may access to support this child. Other categories of funding accommodate children with a diagnosis of Autism, Multiple Disability and other specific disabilities, which tend to be life long. Of the two levels of funding available to schools for students with behavior problems, students with moderate to severe behavior (i.e. Level II) and those with severe to profound (i.e. Level III) require written submissions and have application deadlines each school year (see Appendix C, description of provincial Level II and III funding categories). The primary difference between the two levels is the severity of difficulty experienced by the child with EBD. As a result, Level III funding is appreciably more than Level II funding to enable more support to the child. Applications for funding require specific information regarding the child's emotional behavioral difficulties, detailed information about what schools have attempted to do to help the child with EBD and involvement by outside agencies. These funding applications must be reviewed and signed by parents, indicating they are aware of the difficulties and the planned interventions, and that they agree to the request for funding support in the school setting. The Level II funding application must detail any diagnosis and treatment the child has been given, as well as the plan proposed by the school to address the Emotional Behavioral Disorder in the school setting. The Level III application also requires a detailed, 24-hour plan for managing the child's behavior in the home and community setting. This intensive level of support also necessitates community supports for the child and/or family. The 24-hour plan includes a description of the treatment plan as well as the people/professionals providing support to the child. This

plan must be reviewed on a regular basis (e.g. every six weeks throughout the school year) by a team involved with the child and all levels of involvement around the child are expected to participate (e.g. parents, school personnel, mental health services, family services, justice). The specificity of the funding requirements ensures that a plan is made by school personnel for a child with EBD and that his/her parent is fully aware of this plan.

Changes in Educational Policy in Manitoba

A recent amendment to the provincial Public Schools Act ensures that all children in the province of Manitoba are provided appropriate educational options (Appropriate Educational Programming Regulation, 2005). Among the variety of disabilities this legislation addresses, children with EBD are a uniquely challenging population. This group is one of the most difficult to include in regular classroom situations without adequate supports and programming. Part of the emphasis on their inclusion has been to expand and support the role of parents in planning for these children. This involves moving beyond an era when teaching professionals decided an educational plan that was unilaterally administered to a child. Current best practices require a process-oriented model where parents are included in the assessment, planning and evaluation components of educational programming.

Trends in Mental Health and Education

While there are vast amounts of literature available on strategies to deal with Emotional Behavioral Disorders in the school setting, there is great variability of opinion on best practices for this population mainly due to the difficulty in conducting research with such a variety of children in a multitude of settings. In the past, segregated

programs that provided intensive support for these children in smaller, specialized settings were the norm. At present, the emphasis is on inclusion of students with EBD, but this approach is not universally understood or consistently applied. Many educational professionals including teachers, administrators, and paraprofessionals working in a particular classroom may have a good relationship with and understanding of a child with EBD and manage him/her well in one classroom setting. Yet when this child moves to another setting, often even within the same building, s/he may experience significant difficulties.

Medication as a Treatment Strategy

Some of the most common types of intervention for children with EBD include educational and behavioral interventions such as Cognitive Behavioral approaches (i.e. behavior shaping through positive reinforcement coupled with cognitive strategies such as self talk); social skills training and anger management, parenting training and multi systemic treatments. For children with the most severe behavioral challenges, an increasingly popular alternative is medication for management when many of these other strategies have not shown significant improvement. McLennan (2006) suggests that functional impairment may warrant intervention but the nature of the intervention can vary and one option may be medication. Medication use appears to be more acceptable in light of increased understanding of significant differences in brain functioning in children with behavioral difficulties. When other interventions do not show significant improvement, a welcome explanation is that medication can provide a solution. This explanation is better accepted when medication is seen to correct an imbalance or help the brain to function more normally. "Increasingly, we are moving from a time when it

was common for people to be ashamed of mental illness to a more widespread recognition that we are dealing for the most part with brain disorders rather than simple character weakness and dysfunctional homes” (Jensen, 2002, p. 46).

The greater societal trend is to increasing acceptance of prescription medication to address many health related problems. This is reflected in the school system in that medication to address Emotional Behavioral Disorders has becoming increasingly evident. Gadow (1997) claims this increase in psychotropic medication use has many explanations including the broadening of diagnostic categories, application of physiological explanations for childhood psychopathology, new drugs, financial concerns, “...and a society that appears to be growing ever more sanguine about not caring by using medication as a substitute for education, habilitation or skill acquisition”(p. 230). This view has considerable contention associated with it, especially because it focuses on the use of medication with children, a group who are viewed as in need of more protection and are considered more vulnerable. Where previously the topic of medication for a child’s behavioral problems was initiated in a physician’s office, increasingly it is a conversation that begins in the educational system. These alternative conversations begin when teachers suggest to a parent that the behavior of their child is unmanageable and in need of something beyond environmental changes in the classroom, or when parents become weary of schools complaining that their child’s behavior is unacceptable, or when children taunt one another about taking, as they commonly refer to as a “chill pill”. This is a reference to a substance that calms or reduces behavior. It is difficult to distinguish which has become the predominant factor – the visibility of

children with Emotional Behavioral Disorders or the fact that medication is increasingly turned to as a method to address the difficulties.

It has been suggested that between six and nine percent of preschool children have serious mental disorders that are quite responsive to medication (National Institute of Mental Health, 2000). Use of psychotropic medications became notable in the 1970's as more and more emphasis was placed on outpatient treatment. Between 1990 and 1995, use of stimulant medications doubled in children aged five to eighteen (Safer in Pescosolido, Perry, Martin, McLeod, & Jensen, 2007) while it tripled among preschoolers (Zito et al. in Pescosolido et al., 2007). "Parents of students with (emotional disorders) report that about half take medication for their disability" (Bradley, Henderson, & Monfore, 2004, p. 212).

Forness and Kavale (2002) suggest that as a result of the prevalence of medication for childhood mental health disorders, a new model of special education is necessary to accommodate the growing reality of medication use for Emotional Behavioral Disorders. They suggest a model that better integrates the fields of education and medicine in terms of screening, diagnosis and treatment in the best interests of children with Emotional Behavioral Disorders whose parents have opted to use medication as a treatment strategy. While these authors address primarily Attention-Deficit/Hyperactivity Disorder (ADHD) and the stimulants that are often prescribed to treat it, other medications are used with children as well, including selective serotonin reuptake inhibitors (SSRIs) for anxiety or depression. They show a good clinical response rate - on average, in 60 to 70% of cases (Forness, 2003). Forness and Kavale (2002) reiterate the efficacy of medication for ADHD has been proven in many studies, and claim that to not recognize stimulants as an

important part of treatment for ADHD is negligent. Due to the success of different medications to address a number of mental health concerns, Forness and Kavale (2002) emphasize the need for both medication and behavior approaches to be considered in the treatment of EBD rather than one approach over the other. The National Association of School Psychologists asserts: "Although the use of drug therapy with children has increased tremendously, it should only be recommended as part of a comprehensive, integrated treatment plan including nonmedical interventions, such as counseling, family therapy, and behavioral interventions at home and in school" (Goldstone & Valley-Gray, 2004, p.1).

The challenge for education is not only how best to include children with EBD, but also their treatment. This requires that school system be supportive of the parent(s) who ultimately manage the treatment and to acknowledge their perceptions of satisfaction with their intervention choices. Given these considerations, increasingly there is a need to learn more about parents' perceptions of the role of medication in treating EBD. The purpose of this study is to elicit information from parents of children labeled EBD about their views on the use of medication to treat the emotional behavioral disorder. Research questions that will be explored – from parents' perspective – include:

- What are the factors that influence parents' acceptance of medication for EBD?
- What are some of the barriers to continued use of medication to treat EBD?

- What is the nature of the relationship between parents and schools where children are funded for EBD, and specifically, for those children treated with medication?
- In what ways has medication helped or hindered their child's behavior?
- In what way, if any, has school impacted parents' beliefs about the behavior of their children?
- Has Appropriate Educational Programming legislation and the process it mandates, helped parents support their child's needs?

Chapter 2 will review literature that is important to understanding the concept and prevalence of EBD. As well, theories relevant to conceptualizing how parents perceive EBD and its treatment with medication will be explored.

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CHAPTER 2

Review of the Literature

Prevalence of EBD

Knitzer (1992) claims serious emotional disturbance is largely underreported in the literature and suggests conservative estimates place its prevalence at 7% of all children and adolescents. Canadian statistics suggest anywhere from 2 – 18% of the student population manifest behavioral disorders due to Conduct Disorder, hyperactivity, somatization and emotional disorder in children aged 4 to 16 years (Shatz, 1994). Tainting this prevalence argument is the disparity in definitions of Emotional Behavioral Disorder (EBD) between provincial departments of education. If there is no agreement on exactly what it is, how can we know how prevalent it is? Dery et al. (2004) report the incidence of behavioral difficulties in Canadian elementary aged children has tripled from 1985 to 2000, from .78% to 2.5%. Traditionally, EBD includes externalizing behavior disorders; however, there is some contention internalizing disorders such as Generalized Anxiety Disorder and Depression should also be included.

The concern about children, medication and the role of schools has hit mainstream society and is not confined to the parents and schools affected. A recent popular media (Canadian Broadcasting Corporation, January 25, 2007) broadcast a half hour program regarding separate cases of youngsters in Toronto and Montreal who were displaying significant behavioral difficulties in the school context and whose parents were debating the merits of medication use to address these behavioral difficulties. While the psychiatric diagnoses were different (i.e. Anxiety and ADHD), the commonality shared between some of these parents was the anger and discontent at feeling pressure to

use medication to address these difficulties at school. Three of the four families featured were vocal in their displeasure with the suggestion that medication was an intervention that their child required in order to receive an education. The program suggested that while medication use has increased across society for many different conditions, there is a subset of parents who feel considerable pressure to accept this treatment option in order to be included in a universally administered program such as education. These parents resist the idea of placing their children on medication for many reasons that range from cost to concerns about the impact of use on the child to fears that medication use masks or diverts the focus from effective problem solving.

This dilemma regarding the decision to use medication as a treatment is compounded by the fact that a chemical solution alone is not sufficient to eradicate Emotional Behavioral Disorders – they are often difficult to treat effectively. As well, any time a chemical is introduced to the human body there is a cost-benefit consideration. Is the cost worth the benefit? Is the behavior so resistant to other interventions that it warrants a chemical intervention? This is the decision of the physician, in concert with the parent with increasing input from the educational system. Physiological side effects and long-term effects on the child's health and well-being are always a consideration and require vigilance on the part of the parent and physician. Ideally, follow up by the physician is comprehensive and frequent. For example, due to the many concerns regarding the high frequency of the ADHD diagnosis and "significant controversy about prescribing stimulant medication" (Canadian Paediatric Society, 2002, p. 693) the Canadian Paediatric Society and the American Academy of Pediatrics (2000) issued guidelines regarding diagnosis and use of medication to treat Attention-

Deficit/Hyperactivity Disorder. Parents, who opt for medication as a treatment option after trying other alternatives, need to be prepared to visit their child's physician regularly to monitor the effectiveness of the medication. However there is concern that medication is used too frequently and to the exclusion of other treatments. Part of this concern is not only that too much medication is prescribed but also that if only one type of treatment is offered for a particular disorder parents may make assumptions about the nature of the disorder. For example, if only offered behavioral treatment for ADHD, parents may feel that their child can control their behavior with appropriate training compared to children who are offered medication and may be perceived as having less control over their behavior because they require a chemical intervention (Johnston & Patenaude, 1994).

ADHD: Not the Only Category of Emotional Behavioral Disorder

Due to the high co-morbidity of disorders commonly placed under the umbrella of Emotional Behavioral Disorders, much of the literature regarding EBD focuses on ADHD and to a lesser extent, Conduct Disorder and Oppositional Defiant Disorder. ADHD especially is one of the most researched childhood disorders and provides some of the most useful information about the connection between a mental health disorder and school functioning as well as parenting of children with behavioral difficulties. Gadow (1997) provides an overview of the last three decades of research on pediatric psychopharmacoepidemiology and suggests that information on specific childhood disorders and medication use is difficult to collect due to the ambiguity of diagnosis, variability in reporting drug effects and difficulty collecting such information from children and their parents in the community. Firstly, the majority of research on ADHD is conducted in treatment facilities. Many of the participants have already volunteered or

were recruited based upon their willingness to engage in treatment. A less easily researched area involves students who show the symptoms of the disorder, are labeled within the educational system as having these difficulties, but who have not been officially diagnosed. Gadow (1997) highlights that the focus of most studies on EBD includes children who have been psychiatrically diagnosed. Students assigned the label of EBD but not given a medical diagnosis are a less researched phenomenon. Secondly, most of the research on ADHD does not consider the developmental stage of the child. The ultimate goal of most behavioral interventions is self-control. Relatively little research looks at the best practices or sequencing of intervention strategies that best services children with EBD at different ages (Bugental, Whalen, & Henker, 1977). Whalen and Henker (1992) posit that when a child shows improvement in behavior, the treatment rather than the child is given credit. The role of the child needs to be more closely examined.

Parent Beliefs about Treatment for EBD

How parents understand EBD impacts how they respond to their children and what kinds of treatment they believe they need and are willing to accept. Much of the research regarding EBD is with children diagnosed ADHD. Johnston and Freeman (2002) found that parents who held more reasonable beliefs about ADHD (e.g. ADHD is a neurological disorder) had more effective parenting strategies than parents who had unreasonable beliefs about ADHD. When the beliefs were unreasonable (e.g. ADHD is caused by allergic reactions), parents often waited longer to get help or obtain a diagnosis and held the child more accountable for the symptoms exhibited. When parents understood ADHD to be more biological in nature, they were more willing to look to

medication as a treatment option (Freeman & Johnston, 2001 cited in Johnston & Freeman, 2002).

How parents view this disorder can also effect their beliefs about parenting. For example, Hoza et al. (2000) cited previous work by Elder (1995) that parents who feel efficacious in their parenting will work harder, even with multiple stressors, to provide positive experiences for their children. Hoza and colleagues found that when both parents were asked about their parenting style, “self reported use of dysfunctional discipline (e.g. reactive parenting, laxness and verboseness) predicted children’s treatment outcome” (p.578).

Treatment for ADHD or other disorders that fall under the EBD umbrella can be critical to how parents see the disorder as well as how they respond to their children. Thirty years ago, Bugental et al. (1977) suggested that by taking medication to address behavior, children would minimize or devalue their own efforts to control their behavior. These authors suggest that treatments for children should be matched to the attributions of the parents.

When schools and parents have exhausted all other options to address a child’s behavioral challenges parents are often pressed to consider the medication treatment alternative. “Best practice therefore indeed requires at least some consideration of both behavior and medication treatments for children with significant or emotional or behavioral disorders. The timing of each however, is critical” (Forness, Kavale, & Davano, 2002, p. 173). The severity of a child’s behavioral symptoms often determines how willing parents are to accept treatment (Reimers, Wacker, Derby, & Cooper, 1995). Past experiences with counseling and previous medication use is mildly correlated with

the decision to use medication and counseling to treat ADHD (Rostain, Power, & Atkins, 1993).

Also of note, are the verbal and nonverbal messages parents pass on to children who are being treated with medication. These messages impact the child's attitude and compliance to treatment. Parents' positive attitude is one of the most influential factors in whether a child continues to receive a given treatment (Petti & Sallee, 1986).

Given that children can rarely successfully implement a treatment independently (e.g. cognitive training), parents' beliefs and perceptions are critical to successful management of disordered behavior (Abikoff cited in Hoza et al., 2000). If as earlier suggested, independence and personal responsibility in treatment compliance becomes more likely as children age and move into adolescence, then understanding the origin of parental beliefs and the messages they pass on to their children early on, is important.

Current Philosophy in Education

Inclusion is a way of thinking and acting that allows every individual to feel accepted, valued and safe. An inclusive community consciously evolves to meet the changing needs of its members. Through recognition and support, an inclusive community provides meaningful involvement and equal access to the benefits of citizenship (Manitoba Education, Citizenship, & Youth, 2006, p. 1).

Why has medication in education become topical? Firstly, the trend in educational philosophy is toward inclusion and this extends to that population of students who have traditionally been the most excluded – namely, the emotionally behaviorally disordered. Previously, programming for these students with EBD was particularly exclusionary in the form of off site or segregation from the regular student population. Shatz (1994)

discusses the trend towards inclusion as “merging of regular and special education into a unitary, nondiscriminatory cost efficient system to meet the unique needs of all students” (p.15). Shatz details the change in educational philosophy over the past several decades, which has propelled greater inclusion of many disability groups, including children with EBD, within the school setting. The rise in medication use for a wider array of mental and physical health issues has also contributed to this increased inclusive philosophy. Conversely, within the field of special education, the shift from environmental to more neurobiological explanations of disordered behavior has also contributed to the rise in medication use (Forness & Kavale, 2001). Medication has become more widely available and across a wider segment of the population, including children: “Medical advances have allowed children who have various health conditions to remain in or return to regular classes provided they receive their medication” (Warner, 2001, p. 23).

Secondly, parents have become increasingly more involved in the educational planning process. This has happened for a variety of reasons. For children with Emotional Behavioral Disorders we know that singular treatments that focus only on the child are not as effective as treatments that involve parents (Morrissey-Kane & Prinz, 1999). North American society has also invited parents into the planning process within the school context. Within Manitoba, legislation has increased involvement for parents and their approval is often necessary to implement any programming changes.

Documents have been published by the Manitoba Education, Citizenship and Youth that encourage school divisions to invite and support parental participation (e.g. *Working Together: A Handbook for Parents of Children with Special Needs in School* (2004), *Working Together: A Guide to Positive Problem Solving for Schools, Families and*

Communities (2004)). While this trend has theoretically created an opportunity for parents to advocate for these children, it has also meant that more expectations are placed on parents to participate in the school planning process. Recommendations may be made to parents that may fall outside the purview of the classroom teacher – such as suggestions regarding parenting practices or that behavior can be improved with use of medication – that can raise the ire of parents who are subject to demands they may not feel are their responsibility or choice. As such, parents are expected to be more readily available and easily accessed throughout the individual education planning process, a necessity for many children who manifest Emotional Behavioral Disorders. Not only are parents included in the actual planning but they are more entwined in the assessment (pre) and evaluation (post) phases of the process. Thus, parents are often faced with the opinions of the professionals working with children who share experiences of other children and often will share, appropriately or not, what has shown to be effective for many students both inside the classroom and out. Parents may disagree or have very strong opinions on treatment choices. Medication for some types of Emotional Behavioral Disorders, such as ADHD, is a treatment choice that typically has fairly immediate positive results, if it is to have any. Dery et al. (2004) report that there is a pronounced overlap of the symptoms of ADHD with such behaviors as truancy, bullying/intimidation and opposition to adults though it may not have been diagnosed. Bradley, Henderson, and Monfore (2004) claim approximately half of students with Emotional Behavioral Disorders take medication, according to their parents.

Support for Medication

Gadow (1997) summarizes the past thirty years of medication use in children and states that it is difficult to collect data on specific medications used for specific childhood disorders due to the difficulty in accessing this information in community settings and the non-specificity of drug effects. Gadow also reports that drug manufacturers hold information about specific drug products for particular disorders and that this information is not made available to national health databases. The Multimodal Treatment study of ADHD (NIMH, 2000) was the largest controlled study to affirm the efficacy of medication to treat ADHD. Specifically, of the four groups included in the MTA study, the one group given medication (which was more closely monitored and better followed than the typical care afforded in the community group) fared as well as the group who received medication and cognitive behavioral therapy. "...optimal medication management is superior to behavior management intervention alone..." (p.5). One of the possibilities posited for the success of medication is that lower doses of medication may show increased efficacy if coupled with other treatment options (Forness, Kavale, & Crenshaw, 1999). Gadow (1986) suggests medication suppresses negative behavior and makes children more responsive to their environment or in the case of schools, more open to the influence of teaching strategies.

Whalen (2001) summarizes the findings of the MTA study by saying that in spite of the superiority of medication as a treatment, there are further important questions raised by this research, including parents' reported higher satisfaction with treatment that included a behavioral component compared to medication treatment only. Whalen (2001) queries: "What is the contribution of parental satisfaction to treatment outcomes

for children with ADHD? Might the effects of medication be enhanced by taking steps to increase parental satisfaction? More generally, how do parental values and attitudes influence treatment adherence and affect children's reactions? How can parental preferences be included in the treatment decision matrix?" (p.137). Parental satisfaction with treatment for EBD could arguably enhance participation and communication with schools who are so often involved in the development of plans to administer treatment.

Parents' Decision to Use Medication for EBD: Looking at the Pros and Cons

How then do parents come to the decision to use medication as a treatment option for Emotional Behavioral Disorders? Preliminary research by the author (Podaima, 2005) suggests that parents may feel some degree of pressure to choose medication as a treatment option, especially when their child's behavior is severely disordered. Medication is a last resort when all else fails, rather than a first line choice of treatment that is used as a part of an optimum plan of management for an Emotional Behavioral Disorder. There continues to be a general hesitancy in media and literature to consider medication, especially for children, as first line of treatment in spite of its efficacy (Forness, Kavale, & Crenshaw, 1999). Interestingly, even when parents of children with EBD have chosen to use medication as a treatment option for their child, parents may feel alone and unsupported in this decision. Whether this experience of a lack of support in the decision to consider medication comes following failure of therapeutic strategies or at the frustration of those who work with the child is unclear. Pescosolido and colleagues (2007) studied the stigma that continues to surround treatment and medication for mental illness and children. Their findings suggest that adults who have had some contact with mental illness report less stigma. However in general more than half of the one thousand

adults surveyed in the Pescosolido et al. (2007) study believed psychiatric medications affect children's development and that medication flattens children's affect or makes kids more "zombie like" (Abstract, ¶ 1). More than three quarters of these adults believed physicians overmedicate children for normal childhood behaviors; more than half believed medication use delayed problem solving behavior. Similarly, half of the sample believed children who receive mental health treatment suffer exclusion as a result and would have long-term negative effects as adults. However, these beliefs are inconsistent with the view that medication is an important component of treatment, along with behavioral interventions (Barkley, 2006; Forness et al., 1999).

Behavioral interventions within the school system have evolved. Where separate and specialized programs for children with EBD were once the norm, individual schools now need to initiate their own planning process for the child, commonly referred to as an Individual Educational Plan (IEP). This process begins with increased contact with the parent about the difficulties and negative behavior of their child and moves to increasingly more individualized programming. Somewhere during this process medication may be suggested – perhaps by school personnel or physicians/pediatricians. When is this contact and information from a school to a parent perceived as pressure on parents as opposed to a support for them? Ribner, Bittlingmaier, and Breslin (1976) studied parents' perceptions of their children's behavior and how these shifted toward the perceptions of their teachers. This finding suggests that in the case of children labeled EBD, teachers can impact how parents view the severity of their children's behavior. This could have implications for how parents come to the decision to consider medication as a treatment for EBD.

The question also has to be asked, what are the current rates of medication use for emotionally behaviorally disordered children in the Canadian context? Much of the literature available is based on U.S. prevalence rates, and ultimately, American definitions of EBD which are determined at the federal and not state, level.

Dery, Toupin, Pauze, and Verlaan (2004) conducted a descriptive study within selected Quebec school districts to establish the presence of mental health disorders in elementary-aged students receiving special education services for behavioral difficulties. Based on their interviews of parents, teachers, and children, these authors found that of over 300 students in their sample, a large proportion (over 80%) had difficulties severe enough to warrant a DSM-IV-TR (APA, 2000) diagnosis for a Disruptive Behavior Disorder. They conclude that since there are such a high percentage of special education students with behavioral disorders of a severity enough to warrant a diagnosis, mental health and education sectors must collaborate more effectively to rehabilitate these children. Their results also highlight the fact that the commonly used term "Emotional Behavior Disorder" used by educators is homogenous. Use of the term EBD does not adequately explain the nature of the child's difficulty, especially since children with the subset of internalizing disorders (such as depression or anxiety) are rarely included in the EBD population and are therefore not being clearly acknowledged or programmed for. This supports the earlier cited work by Forness, Kavale and Davanzo (2002) that warns education systems need to change to better accommodate the shift towards medication use. Forness and Kavale (2001) also advocate that educators need to become more adept at recognizing, screening and referring to psychiatry for assessment and follow up. They

also suggest that psychiatry needs to be better informed about education and have involvement in a school's treatment of Emotional Behavioral Disorders.

These questions exploring the prevalence and parents' decision to use medication to treat their child's Emotional Behavioral Disorder are the basis of this research proposal.

Missing Links in EBD Literature

Literature on the effects of medication on the behavior of children and the impact of medication use on parent attributions is available (see Barkley, 1990; Johnston & Freeman, 1997, 2002; Johnston & Patenaude, 1994; Whalen 2001; Whalen & Henker, 1980, 1997), but comparatively less is available on other factors that impact parents' decision to choose medication as a treatment option. Pescosolido et al. (2007) reviewed research on children's mental health treatment and specifically medication use, and claim, "...what is most surprising is the near absence of stigma research on children and adolescents" (Discussion, ¶1). This seems to contradict the research that supports medication use, given that it is the parents who must agree – and pay for - its use.

There is also a great deal of literature on management strategies for teachers in the classroom. Medication however, can very effectively change the configuration for such management strategies and ideally, should also include a self-monitoring component. This means that behavior interventions alone cannot simply be compared to medication use. Rather, the point at which medication use begins or is added to various behavioral interventions needs to be examined. Corkum, Rimer, and Schachar (1999) examined the relationship between parents' knowledge of ADHD, opinions of treatment for it and their decision to try a treatment and to adhere to a treatment. This was one of

the only studies to differentiate between trying a treatment and adhering to it. The authors found that while parents' knowledge of the disorder positively impacted their decision to try a treatment (medication or non pharmacological), this knowledge did not necessarily impact their decision to continue or adhere to a treatment. Thus, the more information parents have about the disorder before making a decision about a treatment, the better the chance of accepting or trying the treatment, but not necessarily continuing with it.

Corkum et al. (1999) also found that even though non-pharmacological treatments were rated as the most acceptable to parents, these treatment options had the lowest enrolment and adherence compared to medication treatments. One explanation for this may be that non-pharmacological treatments are more difficult to consistently administer than medication. This research on treatment choices suggests factors that contribute to a parent's decision to *try* medication to treat an Emotional Behavioral Disorder however these may be different from the reasons why a parent *continues* to use medication as a treatment for their child.

The broad umbrella of the term Emotional Behavioral Disorder used by schools can potentially cloud the issue in that there may not necessarily be a specific diagnosis or understanding of the child's EBD but rather simply an identification of disordered behavior (Forness, 2003). As Forness and Kavale (2002) point out, a diagnosis may not be necessary before intervening for the child with EBD at school, which is the supposed "old" model of special education (p.269).

Most of the literature available on medication use is specifically about ADHD and the use of stimulants such as methylphenidate or Ritalin. On the broader topic of Emotional Behavioral Disorders, ADHD is only one subtype. Also within the category of

Emotional Behavioral Disorders are other externalizing disorders such as Conduct Disorder and Oppositional Defiant Disorder. Dery et al. (2004) focused their research on two Quebec school districts and found that of the 324 children receiving special educational services for behavioral difficulties, three quarters (243) met criteria for ADHD, one half (162) met criteria for Oppositional Defiant Disorder and one third for Conduct Disorder (107).

As Gadow (1997) suggests, the topic of medication and its use with children, especially outside of ADHD, is not particularly appealing to most scientists and is given low status compared to looking at the efficacy of medication in controlled studies due to the ethical issues inherent in testing medication on youngsters.

Reasons to Study Parents' Perceptions of Medication to Treat EBD

Johnston and Freeman (2002) state: "how parents think about ADHD is an area ripe for future research and for incorporation into the clinical management of this disorder" (p.7). While this may be an interesting question for students who struggle to manage ADHD, it is even more important to raise this question with the population of students who may or may not necessarily suffer from ADHD, but certainly struggle with managing behavior in the school context. Students who are deemed to be the most difficult to manage in the educational context would appear to be the ones most likely to benefit from medication. What do parents whose children are labeled EBD think about medication to treat their child's behavioral problems? It is important within the educational context to look at how parents' cognitions are shaped. If, as Bugental et al. (1977) suggested, teachers can shape parents' beliefs about the severity of their children's behavior, can they also influence perceptions of medication to treat disordered behavior?

This is not only an issue for clinical management, as Johnston and Freeman (2002) suggest, but also an educational one as well. In spite of the efficacy of medication, is it ethical that the suggestion to parents to consider its use come from teachers?

Whalen's (2001) summary of the Multimodal Treatment of ADHD study highlighted the fact that medication is superior to other treatments for ADHD when administered in a closely supervised manner. However, Whalen (2001) goes on to comment that the parental satisfaction component can possibly heighten success of a pharmacological treatment program. When medication is successfully used and results in a reduction of behavioral problems, parents still have to be satisfied that it is the most positive and desirable treatment option for their child.

Theoretical Models to Understand Parental Perceptions of Medication Use

The elements of three conceptual models from the field of social and developmental psychology are useful in understanding parental views regarding the use of medication to treat EBD, including the work of Whalen and Henker, Weiner, and Barkley. A brief explanation of these constructs will be presented.

1) Whalen and Henker (1997) provide a compelling social ecological model of medication effects that is based on Bronfenbrenner's (1977) model of human development. While their model specifically addresses the use of methylphenidate to treat ADHD, it is possible to use the premise of the model to conceptualize beyond ADHD to other externalizing emotional behavioral disorders such as Conduct Disorder and Oppositional Defiant Disorder and the medications used to treat them. Whalen and Henker claim it is much easier and more popular, to list the psychiatric symptoms that children with EBD exhibit, rather than focus on the contextual processes within which

they occur. These processes are much more difficult to study but are an integral part of how these disorders are viewed and responded to by parents and teachers. Whalen and Henker (1992) suggest that rather than looking at discrete symptoms and behavior, we should be looking at sequences of interactions. Their social ecological model of medication effects (Whalen & Henker, 1980, p. 6) is best described as a series of concentric circles where the center is the observable changes in the child that occur as a result of stimulant medication use. The next outlying circle consists of “more subtle and elusive attitudinal processes in these children and their significant others that affect, and are affected by, stimulant pharmacotherapy” (Whalen & Henker, 1997, p. 343). The outermost two layers of their model (see Figure 1), including: 4.Society and Culture, and 3.Health and Education Practices reflect the broader influences that have impact on the inner two layers, including 2.Child and Significant Other and 1.Direct Effects. Whalen and Henker (1980) suggest that availability and efficacy of medication influence diagnostic practices and decision-making, educational strategies and societal views around what constitutes deviance and what is appropriate remediation. They claim this model is bidirectional, which would suggest that while levels of analysis and core constructs from the child to society/culture might remain the same, components within each level might change. Given that the model was developed in 1980 and elaborated upon in 1997, cultural beliefs such as those surrounding use of stimulant medication to address problems in everyday living (one element cited in the outermost layer of Figure 1) could be very different almost thirty years after its creation. According to Whalen and Henker the impact of cultural beliefs (level 4) regarding health and education practices (level 3) and subsequently on the parent and child (level 2) ultimately impacts the direct

effects of the medication. While the model was developed with specific application to ADHD and stimulant medication it would appear to have applicability to the broader concept of medication use to treat EBD

This model can be used to explain how perceptions of parents and teachers are shaped: that is, as an evolving process, not a single, static decision to use medication to

Figure 1. "The direct and emanative effects of psychostimulant treatment: concentric circles of influence".

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1. From Hyperactive children: the social ecology of identification and treatment. (p.6) by C.K. Whalen and B. Henker (eds.) 1980, New York: Academic Press.

treat Emotional Behavioral Disorders. It is the interplay between teachers, students and parents that impacts when and how the decision to use medication to address behavioral

difficulties is made. Whalen and Henker (1997) explain that it is the beliefs about medication and specifically, about its use with children to address behavior, that impact whether it will be chosen as a treatment. They cite reluctance to treat children with medication, preference to use “behavioral, educational and psychosocial approaches” (p. 343) first before medication with a particular desire to use self-regulation procedures. It would appear that parents feel it is safer and more prudent to come to the decision to use medication when they can be assured other strategies have been attempted and/or will continue to be used with their children in the classroom setting. According to the model illustrated in Figure 1, of equal importance is the process of communication that occurs between the teacher and parent about the child’s performance. While not explicitly cited, an important underlying component of the model would be the communication of information regarding the child to the parent about how a child is performing and at which point communication is initiated by the school. For example, communication that is perceived to be only negative by the parent (such as phone calls to report the child’s negative behavior) may induce a parent to try medication to reduce the behavioral difficulties. However, a parent may need positive communication from the school to continue using it as a treatment. On the other hand, if the parent perceives the communication from school to be positive and encouraging, in spite of negative behavior, then the decision to try medication will be perceived as one that is supported by the school and the chances of continuing the medication and viewing it as a positive intervention, will be increased. Whalen and Henker’s (1980) model allows for both possibilities.

2) The work of Weiner (1986) helps to explain the process that parents engage in when deciding on a treatment option. Weiner employs an attributional theory model where cognition impacts emotion, which results in action. Specifically, the causal explanations one has for a phenomenon influence emotional reactions and expectancies for the future. Morrissey-Kane and Prinz (1999) have adapted this model to accommodate the fact that parents may work as a couple to develop their beliefs about their child's mental health. If they feel incapable of managing or changing their child's behavior, they will feel ineffective and unable to correct it. They may feel stress and believe that their child's behavior is outside of their control, and as such they will be less willing to participate in treatments that involve them. While Morrissey-Kane and Prinz focus specifically on parental involvement in therapeutic treatment, the hypothesis could be made that if parents feel ineffective in their parenting skills and ability to impact their child's behavior; they may be more willing to look to medication as a way to change behavior. Morrissey-Kane and Prinz emphasize the requirement of any model used to understand parents' decisions about treatment to be more transactional, rather than linear, in nature. They do not however, go beyond the involvement of the parent and child in this equation. It could be argued that a missing or additional piece is the role of school personnel and their interaction with parents and how this impacts the transactional nature of the model.

3) Barkley (1990) cites the behavioral systems approach of Mash and Terdal (1998) where there is reciprocity of effects on, and between, parents and children. Barkley's (1990) model goes beyond the dynamics of the earlier noted two models to help understand the more negative effects of Emotional Behavioral Disorders rather than

only the impact of medication as a treatment. That is, it is not just the effects of the medication, rather the negative impact of the disorder that propels parents to consider medication use. Once again, Barkley's model is focused on ADHD specifically, but there appears to be applicability beyond this one disorder to other Emotional Behavioral Disorders. Though Barkley adds other adults who are impacted by the behavior of children into the equation (e.g. teachers) he claims that as the child becomes more difficult to manage, parents and other adults familiar to the child may become more controlling and corrective. Barkley claims that rather than engaging in the typical strategies used to deal with children such as ignoring, repeating direction, threatening and punishing, this hierarchy becomes abbreviated. The adults start to skip over the more corrective or educative stages to the more punitive strategies. Barkley (1990) hypothesizes that parents can become tired of this hierarchy and eventually do not monitor behavior of their child as closely so they do not have to intervene because they feel ineffective in doing so. Fortunately, Barkley cites research that suggests when treatments for ADHD are successful (such as medication), this process can work in a positive direction in that as the child's behavior improves, reactions by adults around the child become more positive and engaging (Barkley, 1990, Henker & Whalen, 1999, Whalen & Henker, 1992). Parents then become willing to re-engage in the corrective, educative stages that earlier engagement typically rest on.

Wiener (1986) and Barkley's (1990) contribution helps to describe the processes that occur at the first and second levels of Whalen and Henker's (1980) concentric circle model, i.e. parents' involvement between the child and medication (see Figure 1). However, Whalen and Henker (1980) contend that their model has considerable attention

and quantitative research to substantiate this level of explanation because it is easier to measure, for example, the impact of medication on academic performance. The wider relationship to the two outer circles of the model (i.e. education and society) is considerably more difficult to study and requires richer, more qualitative research to explore and understand the dynamics between the child and use of medication to treat ADHD. “Those phenomena that have most effectively eluded empirical examination may be precisely those that have the greatest impact on society” (Whalen & Henker, 1980, p. 7).

Conclusion

This section began with a description of the debate regarding the broad contextual definition of EBD. While there are many treatment strategies that focus on behavioral and parenting strategies to address EBD in children, increasingly medication is being considered as an alternative when other strategies and interventions have been unsuccessful. There is considerable literature on the use of medication for treatment of ADHD and to a lesser extent, the other disorders typically found under the umbrella of EBD, including Oppositional Defiant Disorder and Conduct Disorder. Internalizing disorders such as Anxiety and Depression are less frequently recognized as having observable behavioral components that could be severe enough to warrant assigning the EBD label in the school environment.

As a starting point to understanding parents' perceptions of treatments for EBD, the disorders this educational label includes, and their satisfaction with these treatment choices, it is necessary to define Emotional Behavioral Disorder as the basis for determining the population being studied. Rather than using the medical or psychiatric

diagnosis that may or may not have been added to the education system's use of the EBD designation, parents' experiences of emotionally behaviorally disordered students in the school context will be the focus of this study; not necessarily the psychiatric or medical context. Therefore the larger group of parents with children labeled EBD will be the common denominator rather than a psychiatric or medical label. The funding process that supports services to children labeled EBD in Manitoba's education system has been modified with the intention that parents of these children have a consistent experience with being informed and involved in the process of labeling EBD. Ideally, with their involvement, planning and implementing a comprehensive educational strategy specifically designed to address the needs of the child is accomplished. The nature of medically rendered diagnosis is that it comes out of the relationship between the patient and the physician which has traditionally been a private relationship that does not necessarily have a connection to the educational context.

The research that is proposed here will, using a grounded theory (Glaser & Strauss, 1967) methodology, explore the topic of Emotional Behavioral Disorders and their treatment, from the parental perspective. Within this methodology, the research will be conducted in what most closely resembles an emergent design, which is based on Glaser's (1992) model that allows greater flexibility in its data collection process and analysis (Creswell, 2008). Validity is enhanced by use of a sample of students who have met criteria for EBD funding, in that minimum criteria have been met in the definition of the severity of their behavioral difficulties, if not their treatment. Grounded theory is the most appropriate method to use for this research for a number of reasons, including:

- 1) The need for a research strategy that describes naturally occurring events rather than controlling and reporting on particular behaviors. It is hoped that a case study approach will generate grounded theory regarding parental perceptions of treatment for EBD and that it will help to determine relevant variables for future research that might allow for experimental design. This notion of developing theory after research has a number of advantages as outlined by Berg (2007, p. 285), which support use of grounded theory specifically for this research.
- 2) Due to the fact that treatment decisions are made by parents and are naturally occurring choices and treatment plans with children in their home school environment, it would be inappropriate to utilize an experimental design that compared and contrasted types of treatment choices. In order to access all the beliefs and perspectives that are operating for parents in their decision, interviews that allow for exploration are necessary. Merriam (1998) suggests that internal validity and trustworthiness of the research is enhanced when the method of data collection is closer to reality rather than the artificiality of a data collection instrument that comes between the researcher and the participant.
- 3) The goal of this research is to unearth the informal linkages and processes that underlay parental choices in treatment and satisfaction with medication as a treatment choice for EBD. In order to minimize the impact of methodology on reports from parents, the flexibility of semi-structured interview format used in grounded theory methodology is most respectful and thorough.
- 4) Creswell (2008) suggests the grounded theory is a good choice when the research topic or problem is potentially a very private or sensitive one. Grounded theory design in

this research project supports honest and non-threatening access to parents' perceptions and beliefs and allows for open-ended exploration and probing about choices in treating EBD in their children.

Initial data collection through semi-structured interview will help to establish basic information regarding children labeled EBD in an urban school setting. Parents will then be invited to elaborate on their experiences. Chapter 3 will more explicitly detail this study's methodology and interview results.

CHAPTER 3

Method and Results

This chapter will begin by explaining the methodology used to conduct this qualitative study. The latter part of the chapter will summarize each of the seven interviews with parents of students with Emotional Behavioral Disorders.

The intent of summarizing each interview is to describe the parent and the child and their experience with EBD. By portraying each of the seven participants, their individuality as well as their commonality as parents of children with EBD is highlighted. References to dialogue are quoted by line number in parenthesis.

Method

Participants

The study focused on parents with a child who is deemed to be “Emotionally Behaviorally Disordered” (EBD). All of the families resided within a Canadian, urban school division selected because the researcher had familiarity and access to the potential sample. The school division is relatively large (over 17,000 students) in the province and is comprised of a diverse demographic with respect to socioeconomic status and ethnicity. All parents who were interviewed for this study were mothers. Their names as well as their child’s have been changed to ensure confidentiality.

Procedure for Identifying Students with EBD

The students were designated as EBD by virtue of having met criteria outlined by the provincial department of education (see Appendix C). In general, successive layers of committee screening (including the school team, divisional review team, and provincial review team) are utilized in order to ensure that the core criteria for the EBD designation

are met and alternatively, to reject and recommend other alternatives to increased funding support if necessary. Similarly, if a child fits a more appropriate longer-term funding category due to a different, life-long disability they are not funded within the EBD category. Based on the severity of the child's need, students are assigned to a funding category (Level II EBD or Level III EBD) that confers a designated dollar value (\$8,780 per student and \$19,530 per student respectively) to the school(s) attended by the child with EBD. Parents are required to review and sign the funding application prior to its submission to the divisional and provincial team for approval. EBD funding is for a minimum of one year, but may also be granted to a maximum of three years.

Through the use of the Level II EBD and Level III EBD funded student population in this school division, the chronicity and severity of the student's Emotional Behavioral Disorder is established and meets a minimum criteria established by the provincial department of education. Part of the application process includes a review of strategies and/or treatments that the child is currently receiving at the time of application. Parents then should be aware of strategies being used by school personnel with their child.

School based clinical services are available to students, free of charge throughout the province and are typically clustered within the Student Services department of many school divisions. While the provincial funding guidelines for EBD Level II and Level III funding do not stipulate that funded students receive school based clinical services, a large percentage have previously sought or are currently receiving these services, either for assessment or therapeutic purposes. Some of these students may concurrently or exclusively be receiving other community based therapeutic supports.

During the 2006/2007 school year, there was a combined total of 150 Level II and Level III funded students in this urban school division. This includes students from kindergarten through grade 12. Of that number, 47% or 72 students were currently considered active cases, i.e. receiving clinical services, which may include one or more of Speech Language Pathology, Social Work, Psychology or Reading clinical services. Fifty-three or 35% of these students were receiving services at one time in their school history, but did not currently have an open, active file. Twenty-five or 18% of the Level II and Level III funded students had never received school based clinical services from the school division. Statistics were not maintained on the percentage of those students who were using medication as a treatment for their behavioral difficulties. Currently there are a total of 172 Level II and Level III funded students in this school division for the 2007/8 school year.

In the 2007/2008 school year, when this study was conducted, there were a total of 172 Level II and Level III funded students in the school division. Of these, 65 were currently receiving school based clinical services and 36 were ineligible to participate in the study because they were either known to the researcher or attended schools that were provided clinical services by her. The final resulting sample size of eligible funded students for the 2007/2008 school year was therefore 29 students.

Procedure for Collecting and Analyzing Data

To protect confidentiality and freedom to choose whether to participate, clinicians other than the researcher gave a summary of the study to parents of the 29 eligible Level II and Level III EBD funded students. If parents indicated an interest, they were asked to provide their telephone number so that the researcher could contact

them. The researcher then contacted interested parents who gave verbal consent. If they still indicated interest in proceeding, a one-hour interview was scheduled. Informed written consent (Appendix D) was obtained at the time of this face-to-face interview. An interview guide (Appendix B) intended to be a starting point for the interview was utilized though parents were also encouraged to elaborate on their responses. Letters thanking these parents for their participation were sent by the researcher upon completion of the interviews.

Parent interviews were audio taped by the researcher and transcribed verbatim into text by a typist. Once transcribed, a constant comparative method was utilized by the researcher to identify recurrent themes, as well as contrary evidence within and among the seven parent interviews. Constant comparative method is an inductive process where examples and incidents cited within the data (or interviews) are contrasted and compared to other examples and incidents in other interviews (Creswell, 2008). In this study, analysis began with open coding, to discover initial, fairly specific categories and their properties (Glaser, 1992). This step entailed line-by-line analysis where codes were marked on appropriate passages on the transcripts. In addition, observations made during the parent interviews were referenced and included in the analysis to create triangulation of the data.

The researcher periodically wrote interpretative comments and memos to herself to enhance reflective analysis of the transcripts. The self-directed memos were integral to the constant comparative process in that they aided in the development of more general or theoretical coding. It is through this process of noting these interpretative comments and memo writing that the data from each parent participant was eventually analyzed.

Additionally, the process of memo writing also enhanced the researcher's awareness of her own biases and assumptions, and thus contributed to more impartial reporting and interpreting of the results (Creswell, 2008).

Initial codes were grouped into categories based on "similar phrases, patterns, relationships and commonalities or disparities" (Berg, 2007, p. 306). The categories were in turn sorted and analyzed to determine if there were meaningful patterns with particular interest paid to "in vivo" codes, those that "capture experience of individuals in their own words" (Creswell, 2008, p. 449) since these illustrate the emerging themes especially clearly. As data analysis proceeded, then, it moved from identifying initial, relatively specific codes to creating categories that represented more general synthesis and pervasive themes (Creswell, 2008). Interpretative comments and memos led to discriminant sampling of the data by prompting questions that resulted in returning to the transcripts for additional evidence and/or examples. The themes that eventually emerged were considered for relevance to the general purposes of the study: to understand parents' perceptions of medication as a treatment option. Categories were arranged and re-arranged until saturation was reached that is, until categories could no longer be combined or collapsed meaningfully.

Validation is an ongoing part of the grounded theory approach. The descriptions written by the researcher were as rich and detailed as possible so that comparisons between the situations of each of these participants could be as clearly illustrated as possible. Rich description allows those who read this research to determine if the scenarios represent others' real life experiences and whether the findings are transferable (Merriam, 1998). Validity was also enhanced by drawing the sample from students fitting

EBD criteria and including parents who had read and signed funding application forms and thus were involved in decision making regarding the EBD designation. Peer examination (Merriam, 1998) was another strategy used to enhance internal validity.

This study drew participants from a naturally occurring sample. While all of the participants were recruited by the clinician who was assigned to them, this gives a more realistic investigation of children in the regular school population who are experiencing behavioral difficulties, as opposed to many studies whose focus is on children in mental health treatment facilities or in-patient or community based programs. Validity is enhanced by the consistency of the EBD label and the process of assigning it to these children within the school system.

Table 1

Summary of mothers' reports of information regarding their children with EBD

Parent	Child/Grade	Child's Psychiatric Diagnosis	Medication	Knowledge of type of EBD Funding
Karla	David (5)	ADHD	Methylphenidate	Did not Know
Laura	Shawn (4)	<i>None reported</i>	<i>None reported</i>	Level II
Angel	Alex (2) Jack (8)	ADHD, ODD, PTSD	Concerta, Risperdal Clonidine	Level II Level III
Rhonda	Daniel (8)	Anxiety	Prozac	Did not Know

Madge	Bryan (5)	Bipolar, Asperger's, Autism	Risperdal Ceraquil Topamax Prozac	Level III
Violet	Hanna (2)	ADHD	Dexedrine	Did not Know
Lydia	Natalie (2)	<i>None reported</i>	<i>None reported</i>	Did not Know

Results

This section presents summary descriptions of each of the seven participants. Unlike other parts of this research report, they are presented in the first person in order to convey the experience of the participant observation by which the information was gathered. The "I" in the summaries refers to the researcher and her perceptions as they occurred in the interviews. The participants' reports of information regarding their children with EBD are summarized in Table 1.

Parent Interview #1: Karla

The School Psychologist who currently works with David referred Karla for this study. Karla is the single mother of four whose employment consists of part time lunch monitor at David's school. She appears to be in her forties. She was pleasant and easy going and appeared slightly self-conscious in her responses. When I arrived at her house, she welcomed me at the door. The house was tidy but heavy with the smell of cigarette

smoke. Karla's eldest daughter, Sandra, whom she introduced me to, is a teenage mother whose baby boy was asleep in a baby swing in the living room. Karla explained that her daughter was a student at the local high school and had just recently returned to school following the birth of her son. Karla invited me to sit at the kitchen table and sat across from me while I set up the recording equipment. She appeared to be vigilant to the sleeping baby in the next room while her daughter went downstairs to the basement. During the interview, the baby awoke and at times as noted in the transcript, Karla attended to him. Sandra also appeared in the kitchen periodically in her tending to her baby. Close to the end of the interview, the back door opened and Karla's friend entered. This interruption created a natural end to the interview in that I did not want to elicit any possibly sensitive information from someone not included in the study. Overall, it was a busy household even while Karla's other three children were at school.

Karla's son David is a grade five student who had just recently been diagnosed with Attention-Deficit/Hyperactivity Disorder. Karla was prompted by school professionals to take her son to the physician following their concerns that his behavior was problematic. David had, within the month prior to the interview been prescribed methylphenidate to address his attention difficulties.

Themes that emerged during this interview included Karla's perception that the school was very supportive of her and her son and was attentive to his needs and in planning for him. School personnel, forming a team that included Karla, employed a number of strategies or adaptations that included David's access to resources such as the friendship and resource room, support by professionals including social worker, reading clinician, psychologist, and direct assistance from a one to one para professional. School

personnel also included David in a number of out of class responsibilities that included selling milk and assisting in collecting recyclables. Karla reflected on the fact her son is given choices and limits or consequences even if they are warnings of these. Inherent in all of these adaptations is Karla's involvement in planning for David. This planning not only kept her up to date as to David's program, but also helped her to be able to prepare David for what was coming, examples of which included her discussions about medication and the move to junior high (1253). Additionally the school's plans and involvement did not show any sign of interruption with David's diagnosis of ADHD and medication prescription. Interventions and planning continued and involvement even took on a new dimension – that of helping Karla to monitor David's behavior in the classroom so that she could take this information (via completed behavior check lists) to the pediatrician. As well, Karla's involvement in the school environment went beyond David or her other children: Karla also serves as a lunch monitor at the school. This inclusion in the school environment appears to have supported her view that school personnel were positive in their efforts with students in general and David in particular. This may or may not also have contributed to her awareness of other students similar to David: in particular a same aged boy with similar difficulties to David who was taking medication to address similar difficulties. In spite of her involvement, however, Karla did not know the level of funding her son received. She appeared to be assured that she was receiving updates as to his progress and updated application forms.

Karla's own experience with school was fairly positive and she characterized her own difficulties at school as that of being a "slow learner" (473). This may have influenced her goals for her son which were "...just be great at what he's doing and keep

on going” (1217), presumably in contrast to her own perceptions of herself as a slow learner. This empathic theme also was expressed in a number of other ways throughout the interview. Karla made mention of how school personnel knew the difficulties David was going through with regards to his family (799, 806) and her own struggles with deciding about using medication and how the classroom teacher supported her (374). Karla also expressed empathy for the staff in their work with children, her son included. Karla discussed a number of situations where she was mindful of her son's needs, such as specifically doing better with a male paraprofessional because of his father's absence (156).

Karla also readily accessed community supports such as Big Brothers and summer camps and while these are typically brief in nature, she acknowledged David's need for continued support and requested renewal of these services for her son. Karla was also able to advocate for David as to what would specifically help him, even if it meant asking for it over and over again (as evidenced by asking for a male mentor four times).

Karla's reservations about medication use for David's behavior included the possible risk of dependency, primarily related to her experience of a friend, who at 30 years of age was still using presumably the same medication as her son (1223). A month following diagnosis and start of medications, side effects were evident but did not seem as important as the benefits David was evidencing.

Following her perception that medication was a strong reason for his improved behavior, Karla related to David's difficulties in a very concrete manner: the behaviors that were “bad” were observable, antisocial (e.g. aggression towards others, destruction

of property). Similarly the improvements that Karla noted were behaviorally related (e.g. reading more, participating more, completing crafts, fewer verbal outbursts, less violence to others and property). She also reported that a number of relationships showed improvement, including those of David with his friends and sisters. In addition, based on Karla's report that David was able to complete some crafts projects at school that he gave her as gifts; it may also be that her relationship with David also improved.

In terms of the limits that Karla experienced before considering use of medication to address his behavior, Karla stated that she was "at her wits' end" (142) and that David's verbal threats and destruction of property were the extremes of his behavior. With respect to Karla's decision to use medication, she related that the discussion regarding medication was initiated late in David's grade 4 year. While the pediatrician encouraged her to consider the use of medication, she stated that at that point, she did not think that medication was warranted and asked Karla to review the situation at the end of David's first month of grade 5. Of note is that Karla's emotional limit for David's challenging behavior was reached when the stress in her household was presumably quite high: her eldest daughter would presumably had been living in the same household with a new born baby which may also have contributed to David's escalation in behavior. Karla also chose to give David his medication seven days a week; with the type of medication David is prescribed for Attention-Deficit/Hyperactivity Disorder, parents often choose to administer it only during school hours, when the need to focus and attend is at a maximum. Also of note is Karla's belief that David's "bad" behavior was like that of his father who is not currently in David's life (1231).

In summary Karla related information that suggested she felt very connected to school personnel who were instrumental in guiding her to medication use as one alternative among many other strategies to help her son.

Parent Interview #2: Laura

This second interview was conducted with Laura, whose son Shawn is a grade 9 student receiving funding for an Emotional Behavioral Disorder. The School Social Worker, who is new to Shawn's school and who was not the social worker that met with him last year, referred Laura for the study.

When I arrived for the interview, the townhouse was thick with the smell of smoke and the family's cat immediately attempted to gain my attention and as noted throughout the tape-recorded interview, continued his efforts. While the interview itself was approximately 50 minutes, I spent close to 10 minutes reviewing the purpose of the study, consent forms and explained the tape recording equipment I was setting up. My impression was that Laura was nervous and I spent some time asking her about her pets and home while I set up the equipment. It was only after this preparation that I turned on the recording device and began talking with Laura about her son. I felt that she was more comfortable by the time we began the interview.

Laura was pleasant but presented as somewhat flat emotionally. I was not surprised by her admission during the interview that she suffered from clinical depression. I left our interview wondering whose objective had been met. I felt that Laura had agreed to the interview perhaps as a way of soliciting assistance for her situation rather than as a participant in a research project. Her responses to my questions were minimal given that at other times, she offered information that was tangential to the

questions. She detailed very personal family information that I did not request. As the interview progressed, my sense was that I was becoming privy to Laura's perception of this family's dysfunction. In reading through the conversation, I was struck at how much I summarized Laura's words to me. I don't think it was so much that I needed to concisely summarize her comments as much as I was trying to reinforce her actions or the things she had done on her son's behalf and to move on to less contentious topics in line with the research rather than therapeutic elements.

Central to the theme of this interview was the notion that Shawn's father was the cause of Shawn's Emotional Behavioral Disorder (1189, 1201). She reiterated this notion at the end of the interview in case I had missed this point (1294). When I inquired about Shawn's behavioral difficulties at school, Laura's understanding of it had to do with his "shutting down" and withdrawing and his refusal to do work (175). Within the realm of Emotional Behavioral Disorders, Shawn's difficulties constitute what is termed an internalizing disorder as opposed to the much more commonly seen externalizing disorder. In short, behavior that is explosive and outwardly directed is more frequently seen and attended to in school settings than the inwardly directed, withdrawing type of behaviors that Shawn evidences. Externalizing disorders make up the bulk of students with Emotional Behavioral Disorder funding. From a research perspective, I was thrilled to have been referred a subject such as Shawn whose emotional behavioral difficulties were more of a rarity compared to the more classic externalizing disorder. Of note is that according to Laura, apparently Shawn has no formal diagnosis and has been given approval for EBD funding until grade 12. This information made me realize that my study would have benefited from an opportunity to view the actual funding application of

the children highlighted in my study to verify parental perceptions since EBD funding can only be to a maximum of three years.

Fairly early in the interview Laura acknowledged that she suffered from depression. This admission is critical for two reasons: I believe it helps to explain her own personal style of managing the job of raising Shawn and his younger brother (who incidentally also receives funding for an Emotional Behavioral Disorder) and also her diagnosis of Shawn as being depressed, with many of her same symptoms. This theme of Laura's own experience was clearly the lens through which she understood Shawn's difficulties: she saw Shawn as depressed with the cause being his biological father and the expression of this as anger and cutting himself (1201).

Not surprisingly then given her own diagnosis, one of the core themes that emerged during the course of the interview was that of victimization: Shawn is a victim – of his father's neglect, of school bullies, even of his younger brother. Laura was a victim in the relationship with Shawn's father. Laura's supports are minimal – she cited no community supports for her or Shawn, no personal friends and only one cousin whom she could ask for assistance. Perhaps most poignant throughout the interview was the notion that Laura did not ask or actively participate in any of the supports. While she approached Shawn's pediatrician regarding her concern that he might be depressed and even attended sessions with a specialist, from her own report it sounds like she did not actively participate – she listened to him talk (341). In the same way, she indicated that a cousin she could talk to was only an ear, to hear her. School supports appear to have been available but by her own admission, Laura responded when approached or enlisted by personnel there, who would come to her with forms to sign or updates that were being

made. When the school asked her for information about Shawn and what strategies she used at home with him, she was able to give information but I was left with impression that one would have to probe to obtain it. This theme of minimal communication was also evidenced in Shawn's very real attempt to communicate what she sees as his anger: cutting his arms and hands. Again, Laura's own experiences as an adolescent help her to recognize this as his way of communicating anger (388).

This established pattern of communication explains Laura's knowledge and understanding of Shawn's funding at school for the Emotional Behavioral Disorder. Laura did not recollect information from previous schools regarding funding due to the fact his attendance in another school division that did not submit funding applications. Laura knew the current, correct designation (Level II) and indicated that she kept copies of the paperwork generated by the school but did not quite understand the reason for it, implying that the school had given it to her as a way for Shawn to eventually look back at his school history, not unlike her having saved her old report cards. Laura knew and recognized the value of Shawn having been assigned a paraprofessional to assist him at school when he needed it. She acknowledged that the relationship between Shawn and his paraprofessional was a good one and that Shawn would benefit from its continuance to high school. As well, Laura also recognized that the relationship Shawn had with the School Social Worker was a beneficial one that helped him by giving him someone to talk to and her, as a resource, if she decided to use it. Beyond these relationships, the only other strategy the school should employ, from her perspective, was to give him time alone to de-escalate and become less angry a strategy that she employed at home and one that would be very appropriate in a household with a depressed parent who did not access

supports. It was also apparent that Laura was as involved as she would like to be with the school, but was guarded in her interactions perhaps due to her perception that Shawn was previously bullied and this was the reason for altercations with peers and subsequent suspensions, which were therefore not his fault. Faultfinding was also a theme that reappeared throughout the interview. Incidents that Laura related often had fault attached: it was Dad's fault Shawn was angry and had an Emotional Behavioral Disorder. Laura seemed to imply it was the school's fault when Shawn eventually did lash out at bullies who had been bothering him. The school had seemingly at those times, not appropriately utilized her recommended strategy of letting Shawn cool down to reduce his anger (183).

Also relevant in the discussion of supports is Laura's perception of medication to address Shawn's difficulties. Due to her own diagnosis of his difficulties as depression, she sought initial assistance through his pediatrician. It seems she initially wanted to talk about medication to help Shawn. But from her own admission, the specialist did not give her enough or relevant information, apparently making her and Shawn "fall asleep" during the session with its irrelevance (341). As well, Laura's own experience of using medication is to view it as a last resort. She also held a particularly magical notion that at the very least, having medication available but not having to use it makes more one able to cope with depression (640). Laura's own positive relationship with her doctor makes her able to ask for the medication, but she chooses not to use it. Laura prides herself on not using medication for the past several years though she reports she suffers from depression. Thus, she has great ambivalence about Shawn trying medication. I was left to wonder how badly his behavior would have to deteriorate or how far inward would he

have to go to have her consider medication as a treatment option for him, particularly in light of the fact he did not seem to be functioning particularly well at the present time.

In summary then, Laura's own experiences most certainly colored her understanding of Shawn's difficulties and the ability she had to accept assistance to support herself and her son.

Parent Interview #3: Angel

The School Social Worker responsible for the elementary and middle years schools that Angel's four children attend referred her for the study. Of her four children, the three eldest are boys. At the time of the interview, Angel reported that two of the three boys are funded Level II EBD and the third is awaiting application for Level II EBD. The interview focused on her experiences with all three boys as it relates to their Emotional Behavioral Disorders. This interview was an interesting anomaly from a research perspective, because while I had originally sought participants based on one child per family having the EBD designation, in this family, I had at least 2 children and possibly three, with the designation. By Angel's admission, the impact of her children witnessing domestic violence was pervasive – as youngsters and adolescents they continued to struggle in spite of her support, medication and additional community resources.

Following Angel's agreeing to be contacted for participation in the research project, I called her and offered her the option to be interviewed at home or elsewhere. She quickly responded she would prefer to be interviewed outside her home. She indicated that she would meet me at my office and when I offered to pick her up to bring her to the interview, she initially said that wasn't necessary. My initial impression was

that she was very private and independent, wanting to take the bus. However as we talked in the first phone contact, I again offered to pick her up and bring her to the appointment at my office (2 public transit rides away) and drive her afterward. By the end of the interview, which lasted an hour, I realized that her desire to come to my office to be interviewed was probably more a desire to make this an outing or a social event. I also suspect she felt some guilt at doing things for herself- an interview about the kids satisfied on both fronts: the topic was her children and being out in someone's company to discuss her issues over a cup of coffee was a pleasant social interaction. My perception was formed from her comments during the interview that related to her guilt of having social opportunities that her kids did not, a lack of money and ease with accessing resources and being with social service types of individuals.

When I arrived to pick her up, she carefully prevented me from seeing the inside of her apartment by blocking the doorway and asking me to wait for her out in the car. I feared at this point that she might be quite closed about her circumstances in our interview. I also offered to drive her after the interview, whether she wanted to go home or somewhere else. She used the interview/outing as an opportunity to have lunch with a friend at her house and I drove her there following our appointment. I served her coffee before we began the interview and the informality I tried to establish is reflected in my first comment to her in the taped portion of the interview that we would be chatting.

Angel was very candid in the interview and I was left impressed by a single mother who is adept at accessing a multiplicity of services for her children, three of whom are quite needy and display varying degrees of emotional and behavioral difficulties. Angel's connection to the school is a positive one and by her own admission,

her communication with and support of the schools her sons attend is key to their attendance and participation there.

Medication was a way for her boys and herself, to cope. Not only did Angel have a mental health diagnosis of her own, based on the experiences of her ex-husband and other family members' mental illness she was comfortable with and knowledgeable about the diagnosis given to three of her children.

Angel's explanation of medication was based on her belief that medication brought her kids' behavior to the more normal range of their peers and allowed them to participate more fully. She reported that she had resisted use of medication initially, but interestingly when she rated it as a treatment option along a continuum of supports, medication was not the last resort. Rather, she acknowledged that in-patient treatment for their mental health issues was instead, her last resort (391). Again, personal history played a part in this: because an aunt had been hospitalized for depression and undergone electroconvulsive therapy, she was very reluctant to have her son become an inpatient, despite the recommendation by physicians when he was six. By giving medication, it enabled him to remain out of a residential treatment program and within her control rather than being "lost in the system" (403).

Angel clarified that not only was a physician's input valuable to give her children a psychiatric diagnosis, the recommendation for medication was important because she did not want to harm her kids. She also stated schools "want everyone on meds" (1502) seeming to imply it was the institution's global behavior management strategy.

Angel referred quite often to her view that modeling was an important part of her children's behavior and it was a theme re-visited throughout the interview, from her

worries that her youngest (a daughter), would model the behavior of her older brothers (671), to illustrating - or modeling - to me how she tries to be respectful to one of her sons when he does not want to take his prescribed medication in front of peers. In this instance, she showed me how she whispers to him to request he leave an activity to come take his medication (2164). Angel also suggested that her boys modeled the behavior of their father and the negative behavior of older peers. She voiced her worry that she had in some way caused the behavior of her boys (1214). Angel seemed to be struggling with the notion of behavior as a result of modeling yet at the same time acknowledged an awareness of genetic and physiological reasons for her sons' difficulties, stating "they really can't help it"(742).

Angel reported ambivalence about labeling her sons' difficulties and saw it as a necessary evil for accessing services. She repeated this concern a number of times during our hour together: Angel remarked that labels (such as disabled or Emotionally Behaviorally Disordered) were necessary to get help (i.e. Child Welfare and school supports such as a paraprofessional). On the other hand, she implied that they seemed to leave her vulnerable to criticism about her parenting. By giving her sons a label Angel seemed to have a reason to believe her sons could not help their behavior. Thus, not only did a label justify financial and therapeutic supports, it also legitimized their difficulties.

Angel's access to community supports seemed to be based on her belief that community is critical to raising well rounded children and on her own experiences as a child who accessed supports. As a youngster, she was unable to rely on her own family so she turned to the neighborhood – as an adult, she therefore had no trouble requesting and involving multiple layers of services for herself and her children. She claimed she was

always seeking new services (985). In addition, her own experiences of accessing supports made it easier and more desirable to access services for her kids: her philosophy was that medication alone did not help: it needed to be coupled with counseling (1121, 1128). Many times she spoke of the disparity between support systems available in Alberta to the more meager ones offered in Manitoba and her desire to return to that provincial system. Lack of money was a recurrent theme in her ability to access supports for her children. In Alberta the supports were “Cadillac” compared to Manitoba.

Angel identified school supports that focused primarily on flexibility and communication as the pieces that helped her children to succeed. Angel believed those schools that had been involved with her children had been successful when they responded to the needs of her children, especially when that meant not forcing her kids to comply with school rules such as arriving on time. Angel also believed that her communication with the school was crucial to supporting her sons – not only in how the school programmed for them, but what they expected of her and how she could respond to their requests. While she did not mention it as frequently as other parents, her reference to the school being a team, of which she was a part, was nonetheless acknowledged. Angel frequently alluded to a definition of compliance that seemed to vacillate – at times it meant doing what others wanted (e.g. Her kids doing what the school wanted them to do), but at other times it also seemed confused with the concept of flexibility and schools being flexible in their response to her kids. Her notion of consistency and its importance for her children extended from school to home. She talked of the need to have consistent expectations and for her to remain in her current living situation rather than move. I left the interview wondering if she had more recently

acquired the knowledge that consistency was important for her kids, given her determination to remain in Manitoba. Throughout the interview, Angel's philosophy about her boys' difficulties and what worked was when they were "given a chance" (1141).

Parent Interview #4: Rhoda

The School Social Worker referred Rhoda for the study. Rhoda's son Daniel is in grade 8 at a large middle years school that he has attended for the past two years. Previously, Daniel attended an elementary school, which housed a specialized behavior program in an inner city location. In that segregated program for children with Emotional Behavioral Disorders, Daniel would not have required a funding application – the program is funded and Daniel would have instead required an application to the program. Rhoda's unfamiliarity with the funding assigned to her son does not suggest that he has not required support while attending school but rather that it has been in a different format to the current funding structure.

When initially contacted Rhoda agreed to be interviewed and requested that we meet at her townhouse. On the morning I arrived, we met in her kitchen and an older teenage daughter was in another part of the house. Rhoda was pleasant and rapport was easily established. Throughout the interview and Rhoda's relating her journey with Daniel, it became evident that hers and Daniel's has been a long struggle to establish Daniel's attendance at school. Daniel was diagnosed with an Anxiety Disorder one of the main features of which is his propensity to withdraw and refuse to attend school or leave the house for that matter. At present Daniel attends approximately sixty percent of the week. According to Rhoda, his symptoms have included significant fears of him or his

family being hurt resulting in his inability to leave the house. Medication has been a major factor according to Rhoda, in his ability to be “more capable of doing things” (671). Presently, Daniel is in a regular classroom setting but receives one to one support as necessary, outside the classroom. In particular, Daniel accesses the Learning Assistance Room (LAR), a resource type room whose focus is broadly defined to provide a place for all students, including regular students who may simply need a place to catch up, work in small groups or write a test, to special needs designated children who require individualized attention to children, with Emotional Behavioral Disorders like Daniel, who require a quiet place to calm before returning to the classroom. Rhoda notes that the LAR has been a support to Daniel and in fact, she makes the connection that it replaced the specialized segregated classroom that Daniel used to attend in his previous school division. Other supports that Rhoda identifies include rewarding Daniel for work completion and attendance, an individualized education plan that is planned around Daniel’s progress and needs, and paraprofessional support (despite Daniel’s annoyance and refusal to request assistance). Rhoda often referred to the fact that the team met to plan for Daniel – her definition of “team” was broad and included the school team and supports as well as the community based supports that she and Daniel accessed, specifically the Anxiety Disorders Clinic where Daniel has received outpatient treatment for the past two years. Specifically, his primary therapist and psychiatrist, attend school-based meetings to help plan for Daniel. These meetings have been crucial to Daniel’s success – for example, one of the ways in which Daniel’s anxiety disorder manifests is that he experiences a great deal of anxiety regarding eating in front of other people. Lunchtime planning at school was unsuccessful until this information was shared

between the hospital therapist and the school team who could then make an individualized plan for Daniel that allowed him a private space to eat his lunch.

Rhoda indicated that she had no knowledge of Anxiety Disorders prior to Daniel's diagnosis and has no known family history, at least on the maternal side, though she could not say definitively about the paternal side. She claims she had no qualms about medication use for Daniel's Anxiety Disorder – in fact she reports that when Prozac was initially offered as part of a treatment plan through the hospital, she did not even wait for the full explanation from the clinical staff – she agreed before hearing all the information (1414). From her description, the quality of life for the family was so impacted by Daniel's anxiety she was at her wits' end. It is unclear if this was more pervasive than his school based difficulties. Rhoda characterized Daniel's anxiety as a blend of manifested difficulties at home (i.e. behaviors noted included talking back, being angry and frustrated, fighting with siblings, showing mean facial expressions, refusal to leave the house and paranoia that his family would be hurt by electrical outlets and aliens) to more school based complaints that included refusal to go out for recess, withdrawal, and fighting with peers. Rhoda claimed that Daniel simply shut down and refused to participate in school and initially, therapy at the hospital. He would not ride the bus or eat in front of people. When he was younger and attending the previous inner city school, Rhoda was frequently contacted to come and take Daniel home due to his behavior and fighting. Eventually, she simply kept him home out of frustration at having to go get him and empathy for the teaching staff (127). I was left to wonder if she willingly allowed Daniel to stay home because it was the only place he was wanted and where he experienced some degree of comfort, although clearly it was still a struggle for him.

Daniel's own perception of the medication he takes is that they are "crazy pills" that he will not take if not supervised by his mother (465). Rhoda notes that getting the right dosage was a lengthy process that she was often asked to comment on, but she knew when it was having a positive impact when he could participate more fully, by going outside with his sisters, riding on the bus, smiling and being able to joke with his family. Rhoda reports that after two years of individual therapy, Daniel is willing to try group therapy, a step that Rhoda quite happily reports is an indicator that Daniel is "coming out of his shell" (274). Rhoda recognized that Daniel took many of his fears and worries with him to school and had few strategies, such as talking about them, to help deal with them. In fact, she related that Daniel has had incidents of self-harm by cutting with razor blades. She felt this behavior has also reduced in light of his having established an appropriate dose of medication to address his anxiety.

With respect to supports that she identified as helping her to cope, Rhoda included her participation in hospital based therapy, receiving assistance from the School Social Worker, and the tangible assistance regarding funds to access, or the actual transportation to get Daniel to therapy and appointments. She also referenced her attending planning meetings with the school team as both a support to her and Daniel; especially the flexibility the team used in planning for him at present and for his future needs. She left the impression that she may not have had much to suggest to the school as means of addressing some of Daniel's difficulties, but she was willing to try strategies suggested and was eager to have the professionals around the table share their expertise "so everyone understands Daniel" (1074). Regarding strategies she specifically employed to help Daniel at home, she related that she tried to help him to know when he needed to go

to his room for a break to calm him. A very pivotal moment in appropriately assisting Daniel was when he received the diagnosis of Anxiety Disorder. Rhoda implied that diagnosis lead to his receiving appropriate treatment and support as well as an individually designed educational plan that took into account his areas of need. She recollected that the first meeting between all the school and community based professionals was to talk about “how to work with Daniel” (630). She also reported that she “wanted everybody to kind of understand where I was coming from” (652).

While Rhoda has persevered and accessed school and community supports for her son, she occasionally expressed frustration at the slow pace with which he has made progress, although she acknowledged it is progress. Additionally, I would characterize their struggle as one of slowly emerging from isolation: while the very nature of Daniel's Anxiety Disorder is one of self imposed isolation, an interesting side note is that when I asked Rhoda if she was aware of any other children with Emotional Behavioral Disorders, she indicated she did not. However, on the basis of Daniel's description of other children at school, Rhoda commented that she believed these peers had not yet been diagnosed with an Anxiety Disorder like Daniel's. Ironically, as unaware as Rhoda believes she is about other children who have an Emotional Behavioral Disorder, another potential participant in this study lives in the same neighbourhood as her and Daniel.

Parent Interview #5: Madge

The School Psychologist at her son's school referred Madge to the study. Madge opted to be interviewed at the school and many of the references during the interview were to her familiarity with the school supports that surround the office where she was interviewed. The reluctance to be interviewed at home became more understandable as

our time together progressed – Madge stated that she was quite leery of supports available to her and in spite of the fact she was particularly distrustful of social workers, I suspect she felt more comfortable talking with me in an environment she perceives as quite supportive to her and her son. Bryan, at ten years of age, is the younger of her two children in an intact family. He is in grade 5 in an elementary school setting that goes to grade 6. Bryan receives Level III EBD funding and has a number of diagnoses according to his mother that have been acquired over a period of time, including a primary diagnosis of Bipolar Disorder as well as both Asperger's and Autism. In the same way the diagnoses have been acquired, so too has Bryan's current medication regime: he takes a number of medications that have been adjusted and titrated since he was approximately six years of age. Madge is aware of the fact that Bryan has Level III funding and that he receives full time paraprofessional support. Interestingly, she did not ever refer to his difficulties within the vernacular of the school system, i.e. Emotional Behavioral Disorder, and instead, consistently referred to the psychiatric diagnoses he had been given.

Madge's view of medication is that is a very important component of Bryan's ability to manage school and to see himself as successful. The decision to use medication came at a critical juncture: "I knew something had to happen, so we were willing to try it, and were almost immediately shocked at the difference. It was like a 360." (120). Not only did she and her husband note the improvement in Bryan's behavior (i.e. fewer outbursts whose triggers are not known) but it also allowed Bryan to benefit from talk therapy (1173). "If he wasn't on medication I don't think he would have come this far" (652). Madge was determined to find a reason for her son's "extreme temper tantrums"

in spite of the dismissal of many people that she was exaggerating (56 and 725). Madge detailed her own extensive family history of Bipolar Disorder (210) and sought the opinion of many professionals until she met what she termed a “private” psychiatrist who agreed with her perceptions and therefore diagnosed Bryan with a Bipolar Disorder. Her belief that this psychiatrist is “private” sets him apart from the many organized health and welfare government departments that Madge expressed a great deal of mistrust in and her refusal to return to them for assistance. Medication had been prescribed and attempted prior to the time she secured this psychiatrist in spite of the fact no diagnosis had been given (106). Madge, who also has a diagnosis of Bipolar Disorder, used her own childhood experiences to try to understand the experience – and frustration - of her son (819). Madge’s acceptance of support often seemed to be on the individual level meaning it was the relationship she could have with the professional rather than the service they provided that helped her to accept their assistance. Certainly Madge did view all medical professionals in the same light – she cited examples of doctors and general laypersons where she felt pressure regarding Bryan’s medication and the need to reduce it (665). She argued it had taken a long time to get Bryan to this successful a point and that to remove him from medication “would kill him” (668).

Madge expressed frustration with not being heard and listed many professionals who had not listened to her. In the same way medical professionals refused to acknowledge her questions about why Bryan could not be diagnosed bipolar (210). Madge recollected that daycares had not listened to her about the behavioral difficulties she dealt with at home (725) and that new staff at Bryan’s school tended to view Bryan as a “bad boy” rather than a child with a disability (383).

Bryan's behavior from the perspective of a disability was a double-edged sword to Madge. While she saw the definition of Bipolar Disorder as a way to understand her son, and undoubtedly she empathized with him given her own experiences, it also seemed to help her protect him by getting him supports (987). Madge struggled with the notion of labeling – if his behavior was due to a disability it gave other parents a reason to see Bryan's behavior as something other than being a bad kid and they would be more willing to let their kids interact with Bryan. Some labels however, were not as well known, and Madge expressed frustration that Bryan's primary diagnosis of Bipolar Disorder is not well understood (1029). Madge had the most to say about the concept of inclusion and frequently alluded to her displeasure at the school for putting her son into a regular classroom more often than not. Madge blatantly acknowledges that she wants to protect her son and says, "I would like to put them (i.e. her children) in a cocoon" (987). I believe she views the label that Bryan has as a cocoon: her next sentence in the interview claims "It took me so long to let them label him and then they put him back in the classroom!" (990).

There were a number of perceptions that Madge described including blame by others of her as a mother to Bryan and the fears that she harbored. Madge expressed a great deal of guilt about her son's difficulties including the fact that Bryan's diagnosis of Bipolar Disorder was in her eyes, passed on to him from her side of the family and she questioned whether she would have had children had she known this would happen (907). Another theme was the blame that she felt others placed on her, and that they saw Bryan's difficulties more as a product of parenting style (91). She however, also acknowledged that not being consistent or giving in to him (351) invoked her own guilt.

Madge expressed fear about transitions that Bryan had to make, in going to junior high school as well as in moving from the “cocoon” of the special needs room to inclusion in the regular classroom. These fears appeared to be based on not knowing what to expect. She feared Bryan’s feelings of failure when these transitions went wrong – she felt he was highly at risk of feeling unsuccessful and that behavior would escalate when he could not meet these high expectations that the school had for his inclusion into the regular classroom.

Despite her fears about transitions, Madge saw the school as supportive and expressed her willingness to participate in school planning and in the follow through of goals for Bryan as well as to try different things that were suggested for his program. In spite of some of the frustration she expressed about the personnel that worked with Bryan, the need to educate them and bring them around to her way of thinking, Madge claimed that she and her husband had no intention of moving Bryan because her experience suggested that other students were not as well supported as she perceived her family (1110). An interesting side note is that Madge was very clear that professionals, who did not share her views or that of the current psychiatrist in how to view or manage Bryan’s disability were excluded from the school planning team (1077). It seems as if the relationships with the professionals determined how connected she felt to them and how willing she was to include them in the planning for her son.

Parent Interview #6 – Violet

The School Social Worker referred Violet to the study. Violet’s daughter Hanna is in grade 2 and is new to the school she is attending. While Hanna is funded for an

Emotional Behavioral Disorder, Violet does not know the category. The interview was arranged to occur after school hours at the apartment of Violet and Hanna.

When I arrived for the interview, Violet and Hanna were not home and I waited in the parking lot. The weather conditions were poor and I imagined Violet had had difficulty driving home given the icy, snowy roads. When I called after fifteen minutes to leave a message, Violet answered and exclaimed that she had forgotten our appointment but that I was welcome to come up to meet with her at that time rather than re-schedule. I felt this constricted our interview in that it was dinnertime and the original appointment could not go beyond an hour, as was promised in the preamble and consent process.

When I arrived, Hanna was home with her mother and in fact, throughout our interview, was in close proximity, which lent an air of trepidation on my part. I was cautious in my questions though it did not appear that Violet was concerned about her daughter overhearing her comments. At her mom's request Hanna went to her room to do homework but she often slipped out into the hallway that connected to the dining room where Violet and I met. She seemed to want to hear the adult conversation and she interrupted our interview on two occasions to ask her mother where her things were. She was a polite youngster who followed her mother's requests and directions. The family cat was thrilled to have my attention and jumped on the dining room table during the interview. Violet shooed him away, which is documented on the tape of our conversation.

Hanna has been diagnosed with Attention-Deficit/Hyperactivity Disorder and is currently prescribed Dexedrine as an alternative to the preferred but more costly Concerta, also a stimulant. Concern during first grade had prompted Hanna to be assessed by the School Psychologist. Specific behaviors that her mother cited as causing concern

included fights that Hanna was having at school, rude language, constant motor activity and inability to settle at school to listen to the teacher, and destructive behaviour. Violet is very positive about the impact that medication has had on Hanna and the improvement she has experienced academically and socially. Violet related her initial fear at the suggestion, made by the School Psychologist and Social Worker, that medication might be a treatment option for Hanna. At the time the suggestion was made, from Violet's accounts, it was in the context of information about ADHD and broader information about the disorder and treatment. Violet was referred to a pediatrician who by Violet's accounts, specialized in ADHD. According to Violet, this access to a specialist was validated by Hanna's own pediatrician who indicated he was not comfortable treating ADHD. I was left to wonder if the fact that this specialist had a waiting list and is very busy helped Violet to be reassured about the incidence of ADHD and use of medication to address it. The recommended physician is indeed a well-known and popular physician whose waiting room is often full. Violet also noted that the specialist gave lots of information and resources and was available to talk to even if it meant keeping other patients waiting (242). The perceived popularity of the physician may have helped to convince Violet to persist in finding the right medication even when the first prescribed medication met Violet's biggest fear: that her daughter would be a "drugged out zombie" (228). After this initial negative experience, Violet allowed an alternative medication to be tried and when an improvement was noted, it "really helped me change my mind after that" (258). The noted improvements in Hanna's behaviour included improved attention and organizational skills, work completion and improved schoolwork (212) according to Violet. She also noted Hanna exhibited improved attitude at home and would complete

homework, as well as fewer fights with peers at school (369). As a result of these academic and social improvements which Violet attributed to medication use, Violet was able to justify not seeking out additional community based supports for her daughter. Violet indicated that the cost of such therapy or other supports and the improvement on medication helped her and her fiancé decide not to pursue community-based supports. When asked how she would rank the things that had helped to make this a better year for Hanna, Violet stated that the change of schools had provided a fresh start, followed by medication and involvement of the School Social Worker, who not only provided her with information and connection to community supports, but also saw Hanna on an individual basis at school.

Violet had moved Hanna from a previous elementary school that had dealt with Hanna's behavior difficulties by having her stay with the principal, apparently often for the full day. Violet claimed that Hanna "needs a fresh start, she needs the reputation wiped away" (460). "Reputation" seemed to apply to Hanna's status among peers, as well as the principal who provided supervision as a way of dealing with Hanna's behavioural difficulties, even when Hanna was having a good day (391). Violet commented that she felt only now in a new school, did Hanna get to have experiences like any other kid (462) and not be stigmatized because of her behaviour.

One of the most important strategies that Hanna's new school employed according to Violet was that they had a plan to deal with Hanna's behaviour which included a hierarchy of responses when she had difficulty (38). Seemingly of equal importance to Violet was the fact that there were regular planning meetings of which she was a part. She perceived these meetings as preparation for, not a response to,

behavioural difficulties. In fact, Violet's perception was that she was talked to first (135) and that she helped derive a plan or was in the position to approve a plan for responding to Hanna at the school which involved all those who worked closest to Hanna (i.e. teacher, paraprofessional, vice principal,) and focused on resolving issues at the classroom level (35) rather than resorting to the principal to manage Hanna.

Regarding Violet's perception of the supports used by the school, she referred often to the assistance provided to her and Hanna by the School Social Worker. Violet was impressed with the credentials of the vice principal whom she felt, had a great deal of experience with children with behavioural disorders. Violet seemed very proud of the fact she sought out information on the topic of ADHD and cited internet, library, as well as the School Psychologist, social worker and doctor as sources she accessed. The theme of developing specialized knowledge about ADHD occurred throughout the interview with Violet – from the people whom she felt most comfortable dealing with in her quest to help Hanna, to her involvement in the school team that planned for Hanna. She also believed Hanna recognizes the improvements and that her daughter's self knowledge was focused on how “she has changed and...is better” (577).

One of the most important strategies that Violet referred to in helping Hanna cope at home was to give Hanna “a breather” (36). Contact from the previous school had been by phone calls, which Violet described as negative and occurring every day (329). Interestingly, she replied that she did not object to phone calls but did not receive any this year because Hanna was doing so well and issues were resolved at school. Violet indicated that she would request information from the school and perceived that she was welcome to informally request updates on how Hanna was doing.

While Violet did not specifically state that it was a strategy she used, she referred to the fact she often put herself in Hanna's shoes to evaluate whether methods the school was using were helping Hanna (387) or causing her to be labeled negatively and differently from her peers.

The stigma of the behavioural difficulties Hanna experienced was a strong theme that Violet recounted. Violet reported that she knew no other children who had ADHD or who had emotional behavioural disorders. The stigma that she perceived her daughter's behaviour had however, had prompted the most significant strategies that Violet had implemented to deal with Hanna's behaviour, namely changing schools and also trying medication. Violet was quite pleased with her observations that Hanna was now a well-liked little girl who no longer had the interpersonal difficulties that she had in the past. Clearly, social relationships were important to Violet and she recognized that the interventions she had undertaken had paid off and Hanna was now evidencing more normal seven-year old behaviour.

It is important to note that Hanna is one of few girls who are identified as ADHD which is typically much more prevalent in boys. In spite of the fact that Violet knew no other children with ADHD specifically, or behavioural difficulties in general, it may help to explain how stigmatized that she perceived Hanna's behaviour was compared to other children her age. In other words, Hanna's behaviour would be considerably more noticeable and therefore prone to stigma because so few girls at the age of seven are identified with this disorder or with behavioural difficulties.

Parent Interview #7: Lydia

The final interview was conducted with Lydia, mother of Natalie a grade two student in a more impoverished area of the school division. Lydia was referred for the study by the School Social Worker whose role with this family, by Lydia's admission, is more one of connection to community initiatives in the neighbourhood to address drug and gang activity than direct therapy. Lydia chose to meet me at my office in another school in the division. Prior to the interview Lydia had many questions about the research and explained that she had a number of relatives who had graduate degrees and were employed in post secondary settings. She empathized with the work entailed in completing my doctoral program having seen her relatives putting in similar efforts. I felt we established a good rapport going into the interview, but of the seven study subjects, I felt the most culturally disparate from Lydia and had a hard time making sense of her understanding of Natalie's difficulties. My overall impression was that Lydia was emphasizing the impact of language delays for her and her children and how these differences took a toll in relationships and misunderstanding.

Lydia was aware that Natalie had funding for an Emotional Behaviour Disorder but did not know the level and she disagreed with the terminology "emotionally behaviourally disordered". She indicated that the behaviours displayed at school included fighting (69), hitting, scratching (340), kicking (363) and pulling hair (1230). Lydia said these behaviours did not occur at home but rather noted other difficult behaviours including screaming and crying (98), becoming upset and needing to be calmed (361). Lydia explained that Natalie's behaviour was not a spontaneous unprompted event but rather a typical reaction to some provocation, usually by other people who had hurt her

(54). It was also Lydia's belief that Natalie's behavioural difficulties were a result of her delayed language development – apparently Natalie had not spoken until five years of age. Much frustration and many behavioural outbursts were common until that time. As Lydia noted, behaviour was the only way Natalie could communicate (87).

However, Lydia acknowledged that she had many concerns about Natalie's behaviour from a young age and had been unsuccessful at getting a diagnosis for Natalie from the medical profession. Clearly Lydia valued the diagnosis of the medical profession more than the label given Natalie at school and stated: "...if that's the way they want to label it, but I wish I had a diagnosis that would say that" (1081).

Lydia's view of EBD then was defined by Natalie's experience and that of another of her children who had had similar difficulties at school. She attributed his difficulties to his "superior emotionality" and "empathy for others" (424); apparently an interpretation she had received in the process of assessment of his abilities, an explanation which she now used to describe her own and Natalie's difficulties as well. Lydia compared herself to her children and claimed they all had a great deal of empathy for others as well as speech difficulties (522, 403). She implied that most people misunderstood these traits.

I believe Lydia's own negative experiences with school and medication clearly impacted her interpretation of Natalie's experiences. Regarding school, Lydia explained (in more detail than I was comfortable exploring in the context of this study) her own experiences of abuse by adults when she was a child: "no one is going to abuse her (Natalie) like I got abused, no way" (659). While Lydia valued education, emphasizing that: "School is #1" (720, 875) she did not seem to trust people there.

Medication use was absolutely not an option for Lydia in her treatment of Natalie's difficulties. However, it is important to note that without a medical diagnosis, it is difficult to conceptualize the idea of medication as a treatment option. Yet, Lydia's refusal to consider the idea was clearly stated as a result of her own experiences with anti-depressants: "I don't believe in them. They're too destructive" (514). I wondered if her view of medication was influenced by her dislike of the illicit drug use in her neighbourhood, something she tried very hard to protect her children from.

Listening and being heard were significant themes woven throughout my interview with Lydia and seemed to be at the core of her distrust of institutions like school and community organizations. In the past she had involvement from Child and Family Services but was unconvinced the organization was always helpful. She had accessed medically based services at the medical hospital and community centre and seemed less guarded about them. Lydia related her own experiences of not being heard: "...no one wanted to listen to me" (887). This was the reason she so strongly objected to misunderstanding Natalie's voice, which Lydia believed had so recently found. Again, Lydia's own experiences are inextricably tied to that of her daughter's and she figuratively claimed that you cannot stop someone's voice: "When they are small people won't listen to what they have to say, then you know things keep on happening bad" (635). "We were you know just little girls and they didn't listen to us" (642).

Regarding communication with the school, Lydia disliked the more frequent phone calls she received about Natalie's behaviour last year because they seemed to indicate to her school personnel's inability to listen to Natalie and hear from her the nature of her behaviour there: "I like that they are starting to listen to Natalie" (780). This

was stated as proof that Natalie was being heard and there were fewer phone calls to Lydia. Lydia also indicated that she does not attend many group meetings at the school due to her own discomfort of being in a group (798, 843). However, she does attend some meetings and when asked about them, Lydia stated: "I go listening, I go listening but then I say my pieces too" (820).

Guilt was evidenced in Lydia's comment that she changed her parenting following involvement by Child and Family Services and that she sometimes was not as consistent or firm as she thinks her children need: "I spoil them too because of my past situation, so I give in a lot" (1097).

Lydia's supports appeared to be strongly tied to her cultural heritage: the focus on family was mentioned numerous times throughout the interview in a variety of contexts. When directly asked what made up her support system, Lydia exclaimed that it was especially the women in her family (683). Another strategy that Lydia relied on to manage Natalie's behaviour was to give her "time out". It was unclear to me if this time out strategy was more to calm or to punish Natalie for her behaviour at home.

Lydia also noted that she closely supervises her children's participation in the neighbourhood as a way to limit their exposure to activity there. Not surprisingly, she had the most success limiting Natalie who appears to be the youngest in the family.

I was struck by the importance of modeling throughout this interview: it really was a key piece to how Lydia understood Natalie's behaviour and how she helped her children and other relatives acquire important values. Her distrust of the school in particular was not only because of her own experiences but I believe because she did not see the school listening to Natalie or modeling how to cope for her.

Much of what she hoped Natalie would learn came from her own exposure to family in her own home, at cultural events and in the community from where her husband's family originated. The notion of modeling behaviour was evidenced in a number of examples. Lydia specifically felt it was important for her children to be exposed to "the good and the bad" from her family (719). She characterized her own children's behaviour as less wild than that of children who lived in the community because the latter "...see a lot more, they see a hell of a lot more" (1159). I wondered if this was one of the reasons Lydia disagreed with the school's observations of Natalie's behaviour – that is, in comparison to behaviour that Lydia and her husband have seen in their experiences, they do not believe their daughter's behaviour is comparatively as severe. Earlier on in the interview, Lydia claimed sending her kids to daycare prior to the start of school was a mistake that she later qualified: "They didn't know what fighting was until they started daycare" (1221). Lydia also believed her tendency to voice her opinion and not be "afraid of peoples' titles" was something that Natalie was "picking up" (595). Lydia also claimed that she "picked up" the habit of swearing from her husband (1024) in spite of not allowing her kids to swear (1026). She also referenced how Natalie displayed "prejudism" toward others: Lydia implied that her daughter was modeling this behaviour from others (556).

It appears that many of Lydia's statements about communication – specifically, having a voice and being heard, as well as her many references to behaviour being learned through modeling are important in understanding her beliefs about Natalie's behaviour at school. Lydia seems to view behaviour as more environmentally influenced than genetically based. In fact, Lydia attempted to gain an explanation of her daughter's

behaviour that was more physiologically based. In the absence of that, Natalie's present negative behaviours at school are more akin to Lydia's past experiences. She actually views these behaviours as a positive assertion of her voice and her feelings. This behaviour is provoked by the negative actions of others. As such, it is no wonder Lydia is so vehemently opposed to the idea of medication which she labeled as destructive because it might minimize or even silence Natalie's voice.

The EBD designation then, pushes parents into a public designation that their child's behavior is considerably out of the realm of normal compared to same aged peers. What parents choose to do about this, and specifically if they will use medication is greatly influenced by their own experiences and beliefs about how supported they feel to choose this option. The following chapter will discuss some of the common themes that emerged when asking parents how they perceived the supports their children currently received at school and how they as parents managed their children and how their children managed.

CHAPTER 4

Discussion

From the comparative analysis of the seven interviews, three themes emerged. The first was about parental beliefs regarding their child's EBD; the second, about strategies used instead of or in addition to medication; and third, about parents' views on medication use. While the original intention of the study was to learn parents' views about medication to treat EBD, it became apparent that underlying beliefs and experiences were crucial to understanding why these parents chose or refused to consider medication. For each mother, statements about medication use reflected both their past experiences and current perceptions about the severity of their child's problems and available supports.

To understand the three themes fully, it is important to clarify how parents themselves defined the behaviors of EBD. All students in the sample met the criteria for EBD as defined by the school division and the province and in this sense, had external validity as cases of EBD. But how did the mothers themselves understand EBD in their children? This question was addressed by having parents identify the variety of behaviors they defined as problematic for their child. The behaviors named primarily included externalizing behaviors such as: lashing out, saying really bad things, being a bully (Karla), defiant, stubborn, disruptive, distracted, refusal to do work/write (Angel), explosive anger, throwing desks (Madge), destroying classroom, mouthy, rude, acting up (Violet), fighting, hitting, scratching, kicking, pulling hair, refusal to attend school (Lydia), shutting down, putting head on desk, ripping binder, breaking pens, cutting himself (Laura), shutting down, non-attendance, refusal to go outside for recess and

lunch, cutting himself (Rhoda). Both Laura and Rhoda mentioned some internalizing behaviors such as their sons "shutting down" and withdrawing. While their descriptions of behavior appear to be primarily considered in the realm of an internalizing disorder, both parents also listed secondary difficulties that were externalizing such as fighting. Such acting out behavior would be disruptive in school and in this sense, matches the more traditional definition of Emotional Behavioral Disorder that tends to garner funding support. Overall, these seven parents mostly described EBD in terms of externalizing behaviors. Even for the two parents who described their sons' behavior as more internalizing in nature (Laura and Rhoda), both acknowledged that physical fighting with peers occurred at school. Laura noted that this was not her son's nature to fight but "...he just wants to be left alone" (Laura, 183). Rhoda explained that her son misinterpreted what his peers said and was sensitive to comments by others. It appears, then, that it is the disruption to others that prompted and resulted in funding support.

Just as Dery et al. (2004) suggested in their study of children with difficulties severe enough to warrant a DSM-IV-TR diagnosis for a Disruptive Behavior Disorder, five of the seven mothers in this study indicated they had obtained a psychiatric diagnosis for their child. It would appear, therefore, that the term Emotional Behavioral Disorder as used within the educational system to designate children with behavioral difficulties, is too broad a term to capture the full nature of the problems that these children exhibit. Perhaps the criteria for EBD funding enables support, but it is only for children who manifest severe acting out behavior, and not as readily for children with more internalizing disorders.

Parents' Knowledge of Funding

Of the seven parents interviewed only three (i.e. Laura, Angel, and Madge) were able to distinguish the type or level of funding that their child received, in spite of having signed the funding application form (i.e. Laura, Angel and Madge). In addition, Laura was unable to describe how long her son had received funding; further probing suggested that she was not aware because his previous school did not apply for funding for him specifically. Instead, her son had been involved in a segregated program that was funded as a whole, leaving her unaware of any of the specifics of his personal funding. Laura did report, however, that Shawn's current funding would last until he was in grade 12. All seven parents were aware that their child had the support of a paraprofessional, but did not know the specifics of the support or the amount of funding. Two parents – Laura and Angel – had more than one child with funding for EBD and each of them knew the funding level for their children, perhaps because there were differences in types of funding and application forms between their children.

Themes Emerging from the Parent Interviews

Parental Beliefs about EBD

Parents of the two children who did not have a psychiatric diagnosis (i.e. Laura and Lydia) expressed a desire to obtain one. Laura reported she believed her son was depressed and had taken him to his doctor as well as a specialist to verify this. She related that this had not been a very satisfactory experience in that no diagnosis was forthcoming; in fact the encounter with the specialist was not satisfying:

“He (Shawn) won’t ever cry and he sent me to a child psychiatric doctor or a psychologist or something I can’t even remember but me and Shawn

went to this guy about three or four times and he literally put us to sleep when we were sitting on his couch so we just never went anymore"
(Laura, 334)

Lydia indicated that she had tried repeatedly since her daughter Natalie was two years of age to have her diagnosed, but with no success. Lydia claimed she wanted to know why Natalie's behavior was the way it was and while she disagreed with the school using the term Emotional Behavioral Disorder, she expressed frustration that she had no explanation for Natalie's behavior:

"I've tried, I tried through kindergarten. I tried. I even had her...I thought for a while maybe pica because she was eating lint and mop things, so she went through testing at Health Sciences Centre and no Autism, nothing, nothing." (Lydia, 308).

Notably, while Lydia described concern over Natalie's behavior since two years of age, she seemed perturbed that the school described behaviors occurring in only that setting and that she did not observe them at home. The behaviour problems at school were described as more severe than those at home.

Lydia was the only parent to express pronounced dislike for the educational label of Emotionally Behaviorally Disordered. Her specific disagreement with the term seemed to hinge on the notion that the more severe behaviors reported to her by the school were, according to Lydia, prompted not by Lydia, but by other people in Natalie's environment:

"They're saying emotional but...that she just reacts on her own, but that's not the case and not what she tells me. She reacts when someone hurts her, you know says something to her mean or she reacts...it doesn't matter who it is. If it's me,

she tells me what I'm saying wrong but you know it's anyone, anyone. Something small might bother her but then when something else happens after that, the way something talks to her, their tone of voice or, you know, then she turns and that's when she fights" (43-71).

In the interview, the terminology used by these parents to describe their child's difficulty was primarily the medical diagnosis given to them, rather than the education-based term Emotional Behavioral Disorder. This meant that the two parents who had not received a medical or psychiatric diagnosis did not have a concise term or concept for describing their child's difficulty. Laura and Lydia did not use the term EBD in the context of the interview to describe their child's behavior.

Whether or not medical diagnosis was the basis of their beliefs it is interesting to note that four of the five parents whose children did have a medical diagnosis related their child's difficulties to genetic links to a particular family member or themselves. Each of these four parents stated or implied a genetic link to their child's stated diagnosis. Karla and Violet described a link to their child's father:

"...his Dad has ADHD so it runs in the family" (Karla, 230)

"...her Dad and like three of his brothers and he's got like five brothers or something like that, they suffered with ADHD, they had ADHD" (Violet, 643).

While Angel questioned whether her kids acquired their difficulties from her:

"Well I seen it you know and it was the kids that, their problems well maybe I got a problem too, maybe I need to be assessed, maybe they got it from me..." (Angel, 1670)

Of note is the fact that each of mothers who made this link was a single parent, and the extent of their child's biological father's involvement was not discussed. Of the other two parents, Madge explained that her son Bryan's diagnosis matched her own and Rhoda was unaware of anyone in her family with a diagnosis of anxiety like her son Daniel. She did not know if his biological father had an occurrence of this disorder in his family.

Modeling.

In spite of their trait-based views, parents also implied beliefs that the environment also affected their child. In particular, many parents raised concerns regarding modeling of negative behavior. Laura spoke specifically of not wanting Shawn to "model" his cutting behavior in front of his younger brother (694) and in fact, she alluded to the idea that Shawn had learned the cutting from watching peers (705). Angel worried that her oldest son was modeling inappropriate behavior for her younger sons (671, 849). Angel indicated that she also tried to model appropriate behavior in her relationship and consistency in dealing with her sons' schools (1244, 1257). This was one of the only references to modeling in a positive sense. Lydia expressed that Natalie was modeling prejudicial behavior that she had "picked up" from others (556).

It is important to realize that beliefs about the influence of environment co-existed with beliefs about genetics. It is also worth noting that their environmental concerns were not only about learning negative behavior as such, but also about their child's behavior influencing others, especially siblings.

The findings of Johnston and Freeman (2002), whose work is focused specifically on children who have ADHD, found that the more reasonable the beliefs of

parents about the disorder, the more effective their parenting. As well, they suggested when parental beliefs were unreasonable the child is seen to be more responsible for the behavior and diagnosis is made at a later age. This could very well be the case for Laura and Lydia, who expressed frustration with their children's behavior at the present time.

It seems that a parent who wants to understand their child's behavior and will seek an explanation or arrive at one on their own. For most of the parents in this study, they obtained a medical diagnosis for their child and opted to use medication as a treatment. The two parents who did not have a diagnosis still needed to make sense of their child's behavior; for them, modeling provided some explanation of why negative behaviors manifested.

Guilt.

While not specifically addressed in the questions posed, guilt was mentioned by a few of the parents interviewed especially as it related to their parenting. Rhoda and Lydia both recognized that "giving in" to their children did not help them and Lydia acknowledged that "giving in" was a function of earlier parenting mistakes that had resulted in involvement of a social service agency. Madge's guilt was the most pervasive and presumably, the least resolved by giving in to her son – she harbored guilt that, had she known Bryan could inherit her Bipolar Disorder, she might have contemplated not having children. She also expressed guilt at the times she was not consistent (351) and when she "gave in" to placate him (351). Madge also talked of how she would "try to look at things through his eyes" (819) as a way of guiding her in making the right decision for him. Violet also spoke of putting herself in Hanna's shoes (387) to gauge whether school interventions were positive or negative for her. Angel declared that she

had felt guilt in the past and that deciding to use medication to treat her oldest son Jack's cluster of mental health disorders helped her to not feel blame:

"I'm not a bad parent you know, and cause you sit there and you wonder well how much am I doing of this, you know? How much have I contributed to their problems and you know I sit back and you know I don't want to blame myself any more. I was blaming myself for so long. I fought for Jack not to be on medication for a year and then once I got him on medication, well I won't live without it" (1424).

These disclosures of guilt highlighted the pervasive nature of an Emotional Behavior Disorder: the difficulties these parents encounter go well beyond the school day and impact family and friends.

Research with children who are diagnosed ADHD and Oppositional Defiant Disorder suggests that parents who believe behavior is more controllable respond more negatively to their child's behavior (Johnston & Patenaude, 1994). While Angel was the only parent whose child was diagnosed with the combination of ADHD and Oppositional Defiant Disorder, she acknowledged that her guilt was lessened with the use of medication for her child because it improved behavior she saw as part of their disorder. Parents who independently offered that they felt guilty about their child's Emotional Behavior Disorder cited two reasons: those who expressed guilt about their parenting strategies and specifically how they "gave in" to their children (Rhoda, Lydia and Angel) and those who expressed guilt about their role in the inheritability of their child's disorder (Madge). They did not indicate a link between the choice use medication and their guilt. One way to help with guilt was cited by two of the parents, focused on putting

themselves in their child's place to understand how they might feel about a decision or intervention.

Social isolation.

The stigma of their child's behavioral difficulties was a pervasive theme for these seven parents, though each described it in different ways. Madge described her son Bryan's isolation as a result of his behavior the most poignantly:

"But I'm finding it harder to find programs for Bryan's disability and I don't know how our society like we have right now is going to change that. Because unless you see them, in a wheelchair or visible disability it's hard for them to see that. That's what happened in his class when he first got taken out – all the parents are kind of like 'this kid is just bad!' and I felt like we were having Hannibal Lecter through the halls. That's how bad it was getting to be. And it has taken up to now that some of the parents will actually let their kids interact with Bryan, that they understand it is not a 'bad' issue, that it is a disability" (p. 44).

While Madge was most vehement in comparing of her son to the psychopathic movie character in *Silence of the Lambs*, she was also the most vocal of the seven parents in her preference to have Bryan remain in a more segregated setting. Of note was that in the school where he attended, Bryan was often placed in a specific Special Needs area that welcomed many children with physical and cognitive disabilities. Madge preferred that Bryan's time was limited in the regular classroom setting. For her, this was a way to protect or (in her words) provide a protective cocoon for him:

"I would like to put them (Bryan and his sister) in a cocoon. I have come to realize that you can't, that you have to let go. It's harder with Bryan" (987).

Violet described how her daughter Hanna was stigmatized by the previous school she attended specifically, because her behavior was so negatively viewed by peers: *"I also don't want to see her like this at school, you know, not have any friends and I've seen that already"* (230). The decision to isolate Hanna from her peers during recess and other unstructured times because of her behavior resulted in her spending much of the day in the principal's office. It was due to this stigma that her parents decided to change schools and have Hanna begin a trial of medication for recently diagnosed Attention-Deficit/Hyperactivity Disorder. Violet felt that these two strategies combined were necessary to allow Hanna to be treated and therefore to behave as a normal seven year old:

"I think it was the change from the schools because she needed a fresh start. She just had a reputation, so even if she was to change meds and stuff and she was better, that reputation wouldn't change even through to grade 6. It was the change and the fresh start for her definitely and I think the meds help out quite a bit" (353).

Violet felt that these two changes had allowed Hanna to make more social connections and feel more successful.

This study's sample represented the general tendency of girls to display fewer behavioral difficulties than boys in the school setting. Wagner et al. (2003) claim that eight of ten children labeled with EBD in early and middle years are male (Bradley, Henderson, & Monfore, 2004). Of the seven parents in the current study, two were

mothers of girls, and both of the girls were in grade two. As noted previously, Hanna was prescribed medication for ADHD and there had been, according to her mother, a significant reduction in negative behaviors and an increase in social connections to peers. Lydia however, described her daughter Natalie's behavioral difficulties as a result of her communication difficulties. Lydia described how Natalie was often teased and bothered by peers at school. She stated that she had Natalie held back before starting Kindergarten due to her language difficulties so that she could access preschool services longer before entering the school system. As a result, Lydia believed Natalie was unhappy that she was not with her same-aged peers: *"I chose to keep her back, but she doesn't like it now...Because all her friends, her age group, are a year ahead of her"* (127). While Lydia recognized Natalie's isolation from peers, she attributed the isolation to Natalie's poor communication skills rather than to the negative behaviors that were documented in the request for EBD funding. This is a more indirect cause of social isolation than reported by other parents in this study. The other parents acknowledged the negative behaviors their children exhibited, but these were seen as resulting directly in isolation. Lydia emphasized how other children did not understand Natalie or her motives, and reasoned that the misunderstanding frustrated Natalie and provoked her into displaying negative behaviors. Lydia stated that behavior is Natalie's communication (89). Thus while Lydia identified the isolation her daughter felt as a result of negative behavior, she was reluctant to address or correct it because it took Natalie so long to develop a voice. Lydia disagreed with stopping Natalie's self-expression. Lydia then defined Natalie's behavior as a positive trait – and one that she herself shared. She did not view it as negative or necessarily in need of change.

Karla spoke of the isolation her son David experienced as the “bully” at his school and how it was not until the use of medication that he was able to form positive social relationships with peers and be a part of school clubs and activities. Even at home David’s negative behavior discouraged activities between him and his sisters, but after starting medication, his mother reported improved relationships with his siblings:

“He used to go outside lots and play but then sometimes he’d get in trouble...but now he’s more going out, him and his sister, his twin are spending lots of time together and you know doing things with their friends together....” (974).

Karla also spoke of how David’s behavior settled with the start of his medication so much that he could focus and complete art projects. By displaying them to the interviewer, there was a sense that these gifts to her from David had helped their relationship as well (936).

Laura spoke of how her son was victimized and bullied and said that this isolated him and caused him to respond uncharacteristically by fighting back to defend himself (234). Rhoda’s son Daniel, by virtue of the specifics of his diagnosis of anxiety, was often isolated and in fact, his fears were diminishing his contacts with so many facets of his life that he was quite limited. Rhoda also acknowledged that she kept Daniel home or supported his self-imposed isolation, when staff from his previous school called about his behavior on the rare times he attended. She claimed she did not want the school to see his “bad side” (843) and implied, by her comparison to his current school, that he was not wanted at this previous school (158).

The mothers of two of the children designated EBD spoke specifically of the stress of school personnel contacting them with reports of their children's behavior at school:

"I was having problems at work then too, at my old job and it was very hard for me to come home and hear this and deal with what I was dealing with at work and I was constantly going to bed right after she would go to bed at 7:00...It was like 'I can't handle this'...it was rough, it was really rough "(Violet, 406).

Likewise, Madge expressed her stress regarding Bryan's difficulties in daycare at four years of age and how his expulsion from the program there created stress:

"I had to leave work. I couldn't...everyday it was something else. I couldn't go to work. I would worry about him all day and then go there and think, 'what's happening today?'" (234).

All seven parents spoke of the social isolation their children experienced as a result of their Emotional Behavioral Disorders. Not only were specific school examples cited, but they alluded to other situations and environments as well. Some parents offered community examples; others noted strained relationships with siblings. Regardless, each parent shared how their child with EBD experienced isolation as a result of the child's behavior. As well, few of the parents knew of other children who had an Emotional Behavioral Disorder. Madge noted that it was particularly difficult because her son's disability was invisible – suggesting it would be easier if people could see his difference. She mentioned the difficulty that was alluded to by others: the label that stigmatizes these youngsters also helps to define and (to some extent) explain their behavior. Madge talked

of grappling with the decision to tell people up front about her sons' difficulties, or risking his negative behavior and their consequent interpretations. Either way, she believed he was simply stigmatized and seen as "bad", rather than understood.

Future transitions: a concern for parents.

Future transitions were a theme noted by the parents whose children were close to leaving one building to go into another school. Since children who show Emotional Behavioral Disorders frequently have problems adapting to change, the parents' concern about the potential move is to be expected. Madge and Karla expressed concern about their sons' transition to junior high, but only Karla seemed to have had some discussions with staff at David's school – discussions which had begun at the start of this school year and appeared to have helped her prepare David. The lack of information or not knowing what to expect affected Madge: *"That's what scares me about grade 7 because I don't know what kind of funding or anything else follows into grade 7..."* (1053). Rhoda was also concerned for Daniel's move to the high school, but she too indicated that the team at his current school would help her with the transition:

"...these whole meetings are like, they plan up ahead type of thing"

(1166), "to keep him in there because we were all laughing about it, 'Oh

he got this far now we have to keep him in school, like all day'" (809).

An interesting aside is that regardless of their relationship with the school, all parents appeared to value school and wanted their children to attend. In fact, some of the most avidly stressed comments came from Lydia, who was one of the least engaged or positively involved parents in the sample. Several times in the interview she reiterated

that she told her children “school is number one” (719, 1028) and that it was their job to attend (758).

The perception of being a part of the team seemed to help a parent to assist their child in making transitions and seemed to be part of how they acquired information about the move. The team relationship also assisted them in developing a connection to school personnel that supported their child in the school environment. It is interesting to note that of the parents who chose to use medication as a treatment option, the school was perceived as a very supportive environment in which the parents were welcomed.

Among those whose children were anticipating a change of schools, a common concern was their child's adjustment to a new building and new staff, and especially about whether there would continue to be an individualized, yet comprehensive set of services and adaptations. Concerns regarding continuation of support and the personnel who will provide it were raised at the interview. The interviews all happened between late October and early December, still fairly early in the school year. Their concern highlights, however, the need for parents of children with EBD to anticipate and prepare for upcoming transitions and to pass on this support and reassurance to their children. Early in the year also appears to be an opportune time to review supports in place for students and consider to what might work better for the following year in a new school building and peer grouping. Discussions with school staff would also help parents to know how they can be supportive and consistent in their preparation.

Strategies to Help their Children

Jensen (2002) suggests that only half of the children designated with an emotional behavior disorder receive assistance for EBD from their school. Types of support

available then are important to understanding of when and whether these parents opt for medication.

Using paraprofessional support.

Another potential stigma for children noted by parents in this study was the assignment of paraprofessionals to their children. Even though the funding requested focused on providing one-to-one support in the classroom, some parents indicated that their children felt stigmatized by the assignment of an adult dedicated only to them. Angel spoke of how very differently her two boys were in this regard – one needed and sought one-to-one support while the other did not. Madge, in her vocal bid for more segregated programming for Bryan, stated that he worked best in one-to-one situations with an adult. Laura spoke glowingly of the paraprofessional assigned to her son Shawn and how she hoped that this person would be assigned to her son through his high school years. She indicated, however, that this paraprofessional quite skillfully knew how to offer support to others in the classroom so that Shawn was not as obvious in his need for support: “*he’s not just the main focus in the classroom*” (157).

While the parents did not speak negatively of the paraprofessional support their child received, and in fact overall seemed quite positive about their presence, some parents recognized that the attachment of a paraprofessional adult to their child made their child feel further stigmatized. The parents seemed mixed in their reactions: paraprofessional support was viewed as a positive intervention, but how the child interpreted the support and in turn, described it to the parent affected how normal both parent and child feel and how well the support was utilized.

Supports used by parents.

Laura was the only parent to state specifically that she had no supports. All other parents interviewed cited agencies in the community, physicians, school programs and staff, and family members as sources of support in coping with the stresses of raising a child with an Emotional Behavioral Disorder. It is important to recognize that at the very least, each of these parents had a minimum of one clinical support (i.e. the referring divisional clinician) available through their child's school.

How parents perceive available supports is quite varied. All mothers in this sample had accessed a physician for their child's difficulties at least once, though the success of that connection varied among the parents. Jensen (2002) suggests that one reason why these children do not receive appropriate treatments is due to poor doctor-parent communication. All parents in this sample also had at least one divisional clinician (i.e. School Social Worker, Speech Language Pathologist, School Psychologist or Reading Clinician) involved with their child, but their understanding of this person's role ranged from feeling that person was very supportive to believing the clinician was simply an intermediary to other community supports and/or was only there for the child. This diversity may have reflected the differences in the professional background of the clinician who was involved with their child i.e. whether s/he was a School Social Worker or School Psychologist.

Parents who reported use of multiple community supports appeared to have less difficulty interacting with school personnel and said they were more readily available to the school for involvement in planning and managing their child. There was distrust expressed by some parents about community-based services available to them, and

parents who expressed distrust had previous experiences, which they did not feel were positive for them or their child. This is an important point because Level EBD III funding is premised on a 24 hour plan, meaning the school team often coordinates the planning but community support must also be in place to assist in the remainder of the child's day. While school services are voluntary, they may sometimes be the only support a parent will accept. As mentioned already, all of the parents accessed a physician regarding their child's behavior at least on one occasion, but recent publicized shortages in access to general practitioners in the province could limit the ease of access. It is possible that parents' past difficulties with physician accessibility affected how willing they were to consider additional community based services.

Self-isolation or "time outs".

Ironically, even though these parents acknowledged that their child's behavior stigmatized the child, they also recognized that using a "time out" or other type of exclusionary practice was a useful coping strategy for their child. Examples were cited from both school and home settings:

At home:

"He has had a little (difficulty) once, he had a little outburst and he was sent to his room and then after that he was fine...he knew what he did...so otherwise, used to be so horrible. He used to break walls and his door and everything" (Karla, 216).

"...they had me come in and kind of ask me how I kind of deal about things and basically what I told them was if he gets attitude or huffy or

just not having a good day just kind of give him a few moments to himself... ” (Laura, 125)

“ ...cause that’s what he needs is that ten to fifteen minutes even half an hour sometimes just to cool off.” (1163).

“We manage, we just tell him, like go take a break, go sit in your room for a bit, just calm down. He’ll stomp upstairs but then he’ll come down later as if nothing every happened” (Rhoda, 533).

“Yes, she gets angry, like every other child her age. Then its ‘time out and go to your room’ you know?” (Lydia, 362).

At school:

“They put lots in place for him, like you know if he’s all fired up, they know just to back away and let him cool down first before they try and do anything, cause he just adds fuel to the fire, right?” (Angel, 153).

“...even in the resource room when they had him out of the classroom and in the resource room out there, he would still clear that room. But then he knew that the teachers couldn’t do anything to him, retribution wise, even restraining him, couldn’t really do much. It wasn’t until he came down here (to the special needs room with less kids, more isolated) and he felt safer down there, there was less competition” (Madge, 498).

“If there are any issues with her or anything like that they try to resolve them at the classroom level. If that doesn’t help, they take her out, give her a breather, help her there” (Violet, 34).

Even though the stigma of EBD already sets their child apart, parents also recognize that self-isolation is necessary at home and/or school for their son/daughter to be able to cope emotionally with stress that they encounter. Whether the child's difficulty was externalizing or internalizing, each parent saw a need for her child to have brief periods alone as a coping strategy with which no one should interfere. It is not clear from parents' remarks to what extent self-isolation was a strategy of self-regulation or a negative consequence for particular behaviors, nor the extent to which parents understood its occurrence in each of these ways. In other words, were these children encouraged to utilize the strategy as a way of calming themselves when their frustration built or were they sent into isolation as a punishment after an expression of anger/frustration?

As noted earlier, there is a great deal of research on Attention-Deficit/Hyperactivity Disorder and to a lesser extent, other behavior related disorders. Little of the research is correlated closely with the developmental stage of the child. The parents in this study might have benefited from such (non-existent) developmental research. They all recognized the need for their child to regulate and control emotions but there was not a sense of how expectations would be different for younger children such as Hanna or Natalie (Grade 2), as compared to older children like Shawn or Jack (Grade 8). The value of "self isolation" was unanimously seen as a positive intervention among these parents, but how it displayed in the school as compared to home, as well as how it might be better implemented was not clear.

School supports: including parents in planning.

Whether school personnel recognized these parents' knowledge of their children with EBD in program planning was another central theme in the interviews. From these discussions, the degree of connection parents had with schools was probed.

The parents most connected to their child's school viewed the schools as the most positive and team-oriented. Karla spoke of how the school helped her (1034) and "was there for her" (1079) when she made the decision to try medication with David. Many times through the interview she alluded to how she was part of a team and of the planning for David at school; she gave examples such as the attempts to connect him with activities and responsibilities there.

Angel also described a solid connection to the schools. She said the connection helped her to reinforce consistency with her children and she felt that she initiated communication as well as received it about their day-to-day progress and expectations. She too, saw herself part of the team:

"I've always been trying, try to be on the same length as the school, on the same wavelength because if you have support, if you're on the same row with the school then the kids are seeing well maybe it is me or whatever" (261).

Angel expressed appreciation that the school "kept trying" on behalf of her kids, provided, sustained and gave them chances:

"They're really supportive for Alex. They really like Alex and you know they don't hold it against him and they don't treat him wrong because of what he does and they're fair, you know?" (1141).

Angel's perception was that Alex was liked by school personnel and treated fairly. Part of that perception seemed to come from the school's willingness to be flexible and change their plans as necessary, for both Alex and her other children. Madge also noted the school's flexibility regarding plans: "We're always here for meetings and we're always up for whatever they want to try" (815).

Rhoda too highlighted the flexibility of Daniel's school in planning for him and noted that information that came from Daniel's community supports (i.e. a hospital-based Anxiety Disorders program) was incorporated into the plan for him at school (1074). Violet perceived herself as part of the team planning for her daughter Hanna, but she also recognized the dynamic at the school that allowed for this. Her perception was that in Hanna's previous school, one person (the administrator) directed and implemented the plan for Hanna. In the current school placement in contrast, Violet acknowledged her involvement as a parent: "*they always talk to us first, it's not they plan everything, this is what's going to happen and then tell us afterwards, this is what's going to happen*" (135). Violet specifically noted how all the school personnel worked together for all children, not just the ones with EBD:

"...everybody there works with each other regardless what grade the kid is in or regardless of the teacher that they see or they may not see. I mean, they work together and that's good" (436).

Of the seven parents, the two who were the most detached from the school (Laura and Lydia) were also the ones to express the most distrust of the school's ability to understand and plan for their children. Both of these parents acknowledged mental health issues that may have been responsible for their limited relationship or connection to their

children's schools. Laura said that she was often asked to participate in planning meetings at the school, but did not necessarily attend. Instead, someone from the school would bring her paperwork to sign or copies of the information for her. The school, it seemed, made efforts to include her and to ask for information about Shawn, but she did not always respond by participating in the meetings. When she did attend, it seemed directive, i.e. "They had me come in" (125) rather than by invitation. Laura also noted that she did not have other community-based supports beyond the School Social Worker who was assigned to her son, and she indicated that she did not feel this support was really for her use but rather her son. Lydia too expressed that she did not attend school meetings but acknowledged that this was due to her discomfort with group settings.

Research suggests that singular treatments that focus only on the child with EBD are not as effective as treatments that involve parents (Morrissey-Kane & Prinz, 1999), involving parents in educational planning for their child is now considered best practices by many provincial departments of education as well as school divisions. Nonetheless, as found in many of these interviews not all parents of children with EBD participate. In this sample, two parents participated to a lesser degree and did not seem to view participation as positively as the other five. There were clearly individual and personal reasons for their reluctance. Yet both parents indicated wanting the best for their child. Discerning the reasons for their reluctance, as well as learning about their past experiences with schools and social services agencies may eventually encourage greater participation.

Overall, parents in this study recognized and appreciated the flexibility of school personnel to provide alternative strategies with their children. But this did not necessarily mean treatment for the EBD so much as accommodations for it in the learning

environment. Suggesting strategies that help parents feel effective in how they deal with their children is important to the transactional nature of behavior suggested by Weiner (1986) and Morrissey-Kane and Prinz (1999). It appears that there were a number of agents helping these children with EBD: for most of the parents who viewed the involvement of schools positively, it was the team approach that mattered. School responsiveness and inclusion of parents appeared to support them in being effective and consistent in their parenting. Whalen was talking specifically about ADHD but her comments can be generalized to Emotional Behavioral Disorders when she asked: "Might the effects of medication be enhanced by taking steps to increase parental satisfaction: More generally, how do parental values and attitudes influence treatment adherence and affect children's reactions: How can parental preferences be included in the treatment decision matrix?" (2001, p.137). In this study, parents' involvement in school team planning was one strategy that helped them to feel more comfortable and competent in continuing treatment choices.

Accessing community supports.

How these parents perceived their connection to schools was related to their use of community based supports. The services or agencies used by most of the parents suggested that those who had the strongest, most positive relationships with their child's school also accessed the most community-based supports. Angel was the best example of this. She expressed strong ties to her sons' schools, but she also used the widest range of community supports and was always looking for additional ones (985). A possible reason for her approach was that she had previously lived in another, larger Canadian city that had had a very rich network of support services for more impoverished families and she

currently struggled with the comparative scarcity of services where she now lived. A second factor influencing her was the comfort Angel evidenced in requesting supports: she had a wealth of personal experience with them. She recollected that as a child, she had relied on people in her neighborhood to help her cope. Her comfort with seeking out supports translated into being able to request them for her sons without frustration.

Karla, too, readily accessed community supports for David, to the extent that she would request the same support multiple times. When she saw the positive impact that a particular male support worker had on David, she re-enlisted his support as much as she was able (156). Rhoda maintained a strong connection to the outpatient Anxiety Disorders Clinic for Daniel, but also sought additional help in getting him to the clinic when he refused to take public transit. Violet relied on a number of informational sources in helping Hanna, such as the library, the internet and professionals (i.e. physician, School Social Worker, School Psychologist). These services made her better informed about Hanna's difficulties and about Attention-Deficit/Hyperactivity Disorder. She did not, however, access additional supports, as she believed they would cost her too much money.

In contrast to Angel and Karla, Madge was the most discouraged about community-based supports, and gave examples of how attempting to access them but, for one reason or another, not feeling encouraged about doing so. In some cases she distrusted them as a result. She felt her own physician and Bryan's physician were her best supports and she used the Internet for additional information. Likewise, Laura and Lydia both did not access any outside community supports. Laura said her only source of support was a cousin, and Lydia said that the women in her family were her supports.

The research by Hoza et al. (2000) suggested that parents who feel effective in getting things done work harder, to provide positive experiences for their children in spite of multiple stressors. This certainly appeared to be true for the three parents (Angel, Karla and Rhoda) who were trying to access supports and opportunities for their child with EBD while juggling the demands of parenting other children. Since community supports were required for Level III funding, the efforts of these parents to find supports suggested that they were doing so for themselves, and not necessarily as a school requirement.

Views on Medication Use

Parent perspectives about medication use.

It is important to understand parents' general perceptions of Emotional Behavioral Disorders and the social isolation they encounter before considering their attitudes toward specific treatment options, including the use of medication. Their general perspectives provide a way to understand their desire for their child to behave as normally as possible. The despair and chronic struggle described by these parents often underlies the decision to try medication for behavioral difficulties, either after or in conjunction with other therapeutic treatments.

In the cases of these seven parents, five had been given a diagnosis for their child's difficulties and prescriptions to address the behavioral challenges while two continued to struggle with managing and understanding their child's behavior. Both of these parents did not "believe in" medication for their child but would have liked a diagnosis to help understand their child. This suggested that the EBD label may have been useful for school personnel to designate behavioral excess but not parents. Both

parents acknowledged mental health issues of their own and said that their refusal to use medication was based on their own negative experiences with it in treating their own disorders. Lydia was especially clear in saying that her own negative experiences with anti-depressants were the basis of her decision not to consider medication for her child if it was suggested by the physician (514).

Personal histories of medication use, however, varied among the five parents whose children were prescribed medication. Each of these five said that at some point, the behavior challenges became unmanageable, a fact that made trying medication easier, in spite of their fears and reservations:

"I was still thinking that he was getting worse and worse and you know what I thought no I, we have to do something because otherwise, it would be a handful" (Karla, 232).

"Anything, anything, it was like, when they first mentioned to get him on medication, like Prozac or some kind of other medication in my mind I thought 'hey, right on'. Yes I'll do it and then before you can finish you know explaining to me I just said yes, I'll go for it, we'll try it" (Rhoda, 1411).

"I knew something had to happen so we were willing to try it were almost immediately shocked at the difference. I was like a 360" (Madge, 120).

"We were at the point she just couldn't grasp anything. She was not really out of control. She was just not able to sit and focus and listen and do a task, like even if it was just a small task, like pick up your clothes and put them in the laundry basket. She'd throw a fit over that." (Violet, 266).

As for Angel, she saw medication as a last resort, but as a viable alternative to what she saw as the true last resort: in-patient hospital or residential treatment.

In affirming the severity of behavioral difficulties and prescribing medication, the physician had of functions. First, s/he legitimized parents' concerns that behaviors were of a level significant enough to warrant medication as a treatment option. Angel spoke of wanting her doctor to give a second opinion so she could be sure she was not harming her children (1576). Secondly, the physician gave parents a biologically based explanation for their child's difficulties. Angel's explanation for her boys' difficulties was that they had "chemical imbalance" like her (2195) and needed to keep their levels of medication "up" (2218). Rhoda too, felt a diagnosis helped her and the school know "what we were going up against" (883). Third, the physician gave parents a necessary support outside of the school. When Karla initially refused to consider medication as a treatment option, for the school. When Karla initially refused to consider medication as a treatment option, she noted that David's doctor affirmed it was her choice (1351). This suggests that the physician's support of parents' treatment choice may reduce the stress on parents and may help them to make decisions that they feel comfortable with. However, Madge stated that in her experience, doctors listen to teachers more than parents (1095): *"So that's hard because as parents we value what the teacher says, but it is not always on the mark"* (1088).

Laura, who did not want her son Shawn taking medication, acknowledged that medication was the last resort in her hierarchy of treatment alternatives. Apparently she felt he had reached a threshold she deemed necessary for considering medication because she had taken him to the doctor with medication in mind initially. However, somewhere

in the meeting with the doctor she had changed her intention: *"The more I think about medication, I don't want him on medication, I want him to understand. I was on meds for years and I have so far to deal without it for about seven years"* (624). In her own experiences she had been prescribed medication, kept the prescription filled at home, but never took the medication. Her actions suggest she saw abstinence as a test of her ability to take care of herself and she seemed to believe that Shawn should resist medication as well. She seemed to want him to learn from her experience, which had not been positive regarding medication.

As with Laura indicated earlier, Lydia vehemently opposed medication for Natalie because of her own negative experience, and because of the association she had between illicit drug use and the use of medication to address Natalie's behavior. She seemed to believe that the two activities were in the same category (580).

Earlier, in Chapter 2, the question was posed; "Does the medication alternative imply to parents the message that children are unable to control their behavior?" Research by Bugental, Whalen and Henker (1977) suggested children themselves may infer this message; those with ADHD who were treated with medication tended to believe that the medication minimized their own efforts in controlling behavior. The current study did not look at the children's perceptions but it would seem that at least some of the parents did not think of medication as reducing self control; on the contrary they felt that medication helped their child to learn and benefit from non medical interventions such as counseling, (e.g. Rhoda, Madge and Angel). Their attitude may reflect changes in common understandings of how medication works compared to thirty years ago, as well as changes in beliefs about disorders such as ADHD. In any case, for those parents who

chose medication, however, the results suggest they had a positive attitude about using medication. Some parents described difficulty in having their children agree to take the prescribed medication. These were the older students and their parents recognized the need to educate their sons about its purpose.

Consistent with a past interview study of parents (Podaima, 2005), many of the parents in the current study saw medication as a last resort. They expressed a belief that they had reached some emotional limit before succumbing to its use. Barkley (1990) suggested that it is not only the positive effects of medication that help children with ADHD but also for parents to try parenting strategies that work successfully. For these parents, the sequence of events seemed to be this: 1) previously they tried to correct their child's negative behavior but were unsuccessful or ineffective but 2) use of medication as a treatment made them willing to try again and 3) often they then got more positive responses to their efforts. This was the sequence that Angel and Violet seemed to have experienced when they said that their children's behavior did not magically disappear, but rather became more within "normal".

The parents in the current study conveyed a sense of isolation in deciding to use medication to treat an Emotional Behavioral Disorder. Pescosolido et al. (2007) noted the stigma attached to medication and treatment for mental illness in children. The current findings suggest that the stigma exists for children with EBD, and that in addition there is stigma about the behavior that led to the diagnosis in the first place. Medication is a lesser evil, so to speak, than allowing the behavior to continue, with or without other treatments.

Ribner, Bittlingmaier and Breslin (1976) suggested that parents “structured the pattern of their perceptions to become more similar to those of the teacher” (p. 345). Going into this study, the researcher anticipated that parents might indicate that they had felt pressured by schools to consider medication as a treatment option for a child’s behavior disorder. In fact, only one, Angel, mentioned that “schools want to see everyone taking medication” (1502); there were no other references to inappropriate comments or pressure from school staff. Nonetheless, phone calls from teachers and other types of school reports may constitute a more subtle influence on how severe a parent feels their child’s behavior problem to be. In principle, the strategy of calling parents with information is not objectionable: parents simply seem to find receiving phone calls to be a negative experience. Teachers therefore have strong, if only implied, influence in how an Emotional Behavioral Disorder is perceived, managed and ultimately acted on. Madge for example, suggested that she felt the teacher’s “say” was worth more than hers, at least to the doctor (1095).

Corkum, Rimer and Schachar (1999) suggested that information positively influences the decision to try a treatment (medication or otherwise) though it does not necessarily influence the decision to adhere to treatment. They found that non-pharmacological treatments were often stated as the preference by parents, but that these treatments often had the lowest enrolment. In the current study, the results were similarly mixed. Only two of the parents continued to support therapeutic interventions outside of the school setting (Rhoda and Madge who received therapy through an Anxiety Disorders clinic and a psychiatrist, respectively). While other parents supported the work of the

clinician at school, they did not seek outside community based counseling support, or at least did not specifically state that they had.

Whalen and Henker's social ecological model (1997) outlined in Chapter 2, succinctly describes the dynamic for the seven parents in the current study. While Whalen and Henker's model is about the use of methylphenidate to address Attention-Deficit/ Hyperactivity Disorder, it seems relevant to children who are treated with medications to address an Emotional Behavioral Disorder. According to the authors, it is not enough to simply list the behaviors that children with ADHD exhibit, but rather the social context in which they occur. It could be suggested that this advice also applies to children who are diagnosed with other behavioral disorders treated with medication. As illustrated in the parental interviews, the perceptions and beliefs of parents are critical in one of the outer rings of Whalen and Henker's model (1980) referred to in Figure 1 (see page 31 in Chapter 1), influence the child's response to medication, as do the practices of school and health care practitioners. In the current study, changes in the outer concentric circles in Figure 1 impacted the decision at the core, which directly impacted the child and how the child perceives the effects of medication.

Parent fears about medication.

The fears expressed about medication by these parents focused on their perceived sedating effect and the worry that their child would appear like a "drugged out zombie" (Violet, 228). They also expressed concern regarding long-term dependency or as Karla stated, "getting hooked" (324). The concerns about dependency occurred prior to their children beginning medication. Parents specifically described them as occurring when they were contemplating medication use. Apparently, once their child was using

medication, parents' perception improvement in core symptoms, improved and the initial concern for dependency reduced. Thus it was not only the emotional limits reached by parents but also personal experiences with medication and their perceptions that helped decide if they would consider medication.

Note though, that parents who chose medication also acknowledged that even with medication, problem behavior did not disappear but simply came to a more normal range. Madge remarked that Bryan's behavior improved so dramatically with the addition of medication, she and her husband were shocked. Karla also described the improvement in David's behavior as a "total difference" and in fact gave him medication seven days a week, a medical option often given to parents of children who have been diagnosed with ADHD. Karla noted however, that many of the additional supports or opportunities at school were attempted before the start of medication. She therefore saw David's use of methylphenidate as one intervention among many. Angel as well reported that she "couldn't" stop administering medication to her boys on the weekends; doing so would be unmanageable for her (484).

Both Angel and Madge pointed out that therapy needed to accompany medication:

"I mean you can't just, just medication alone don't work" (Angel, 1128).

"And I'm like, 'come on, give me drugs!' (Laughing) which sounds stupid, it's a contradiction. You'd like to be able to talk therapy your children, but you know what? Sometimes you can't. With this kind of disorder, you can't. It's not just the child having a temper tantrum. It's something

chemically in his body that you need to fix first, then you talk to the child” (Madge, 1172).

Violet emphasized that medication brought Hanna’s behavior within the normal range:

“She needs to have friends. She needs to you know, really experience that and now she is, she is experiencing it like any other kid would. And they might have their bad days, have their days when they fight and grab at each other and stuff but she is acting more like a normal seven and a half year old than she was before” (460).

Rhoda described how Daniel was “more capable of doing things” (671) suggesting that his life had become so affected by anxiety that he was missing out on many of the activities typically enjoyed by kids his age such as playing outside. Angel was the only parent to suggest that, “*Nowadays, the school wants everybody on medication*” (1502).

This is an interesting perspective from the one parent who appeared to have one of the closest relationships with her children’s schools. It may also reflect the unusual situation that three of her four children were prescribed medication for a mental health diagnosis.

Explaining medication to their children.

Two of the parents explained to their children why they were taking medication to treat their behavior:

“I just said you know, you are going to have to, you know take some meds, I says ‘It’ll help you know, it’s going to help you, how you’re controlling on you know, your outbursts and everything like that...but it has lit it might make you sick and have a headache and you know, you might not be able to eat....” (Karla, 1162).

"I just said, you know your brain doesn't work the same as your average Joe I said but I said that's just the way it is. I said I have to take medication cause I have a chemical imbalance...so you can fly right and be in less trouble. I said if you're not on medication, what happens? And I get them to think about it and you know and then I don't have problems" (Angel, 2193).

Both of these parents specifically addressed the expectation of reduced behavioral difficulties. Karla described anticipated side effects to help her son David anticipate how the medication might make him feel. Angel used her own experience and the explanation that she had to help her son understand what to expect. She also encouraged her sons' active problem solving regarding their behavior and its effects on her (2212).

Rhoda, on the other hand, related the difficulty in getting Daniel to take medication for his Anxiety Disorder; as he put it, *"God, do I have to take these crazy pills?"* (465). Despite his mother's recognition of how significantly improved Daniel's life was with the addition of anti anxiety medication, she needed to be quite vigilant in administering it to him to ensure that he took the medication regularly. It is noteworthy, however, that the compliance issues expressed by Angel and Rhoda related to the older youngsters in this study.

All in all, as suggested in some of the literature, a positive attitude by parents toward an intervention assists in a child's compliance with the treatment. Within this study, all the parents were mothers and many were single parents. For the latter, there were indications that their child showed behavioral symptoms not unlike their ex-partner and that the diagnosis originated from that ex-partner. This could have been cause for

concern to the self-esteem of the child and possibly to their relationship with the father, especially if the similarity was untrue or misleading. In the context of this study, it is impossible to verify such possibilities. Regardless of the influence of any ex-partners, it was obvious that parents struggled with compliance, and it seemed to need support in this area.

On "Being Heard"

An unanticipated theme to emerge from the interviews with the parents was their repeated references to "being heard". "Being heard" was the frequent reference used by parents to describe the process of others listening and acknowledging what they or their children had to say. In the context of discussing their children, the concern with being heard was usually directed to school personnel and to a lesser extent, the physician who saw their child. When parents felt heard by the school, they implied that a positive relationship resulted, not only with the school but also with the physician.

Although not being understood might be more expected as a complaint about their relationship with their children, in fact parents expressed more concern about it with regard to schools and other helping professionals. Angel, who expressed a very strong connection to the school, commented that the school asked for, listened to, and tried out her suggestions (614). She also believed she could call the school and give them information about her sons. Violet too, suggested that one of the reasons her perception of Hanna's current school was better than the previous one was that she was included in more of the regular school day (52).

Rhoda's references were more indirect, but nevertheless alluded to school's hearing the information she had to give about difficulties of managing Daniel at home.

"I wanted everybody to understand where I was coming from, I told them, I told them everything like I'm pretty much telling you, like they asked about his behavior and everything and I told them..." (652).

Being heard by the school seemed to be the first step in connecting with the staff at school. Karla explained that when her son David had difficulties at school, she was asked to come in to talk with the principal (770), suggesting a dialogue rather than a lecture about the behavioral problems there. Karla also felt that she and David were understood when David's behavior escalated due to his relationship with his father and a family crisis (799, 806).

In contrast, Laura did not the specialist to which she was referred listened well to her concerns regarding Shawn's depression; ultimately she felt that he did all the talking (341). She noted that she turned to a cousin who simply listened and did not respond to: *"But she doesn't really have a lot to say, she's just kind of there for the ear"* (1063).

Madge's felt misunderstood both by the school and by the physician. She felt Bryan's school did not hear her belief that Bryan needed to spend more time in the segregated special needs room, and simply went ahead with their own decision to place him in the regular classroom:

"I was really scared at first, in fact, I didn't want it to happen at all and I was fighting it and they wouldn't listen" (396).

Madge also commented that physicians did not listen to her when Bryan was very young (56). It was necessary, she said, for her husband take Bryan to appointments so that the doctor would listen to the difficulties they encountered with Bryan. She also remarked: *"And the doctors of course are always, 'okay, we'll listen to the teacher'"* (1095).

Lydia's reports of not being heard were the most pervasive and tightly interwoven with her own experiences as a child. In the context of the one hour interview there was little opportunity to explore the roots of her perceptions. If there had been an opportunity, however, it would have been useful to probe Lydia's experiences and resulting beliefs and perceptions. Her comments about being a young girl in school who was not listened to were very vivid when she talked about her own daughter: "*When they're small, people won't listen to what they have to say*" (635). Although Lydia noted that Natalie had not spoken until five years of age, she was reluctant to stop Natalie from speaking out now that she was seven. Lydia's perception was that Natalie was finally being listened to (780) at school; the evidence was that Lydia was hearing fewer complaints recently from the school about Natalie's behavior.

The way that parents were contacted by telephone also affected whether contacts were viewed as helpful or unpleasant. The parents did not object to the phone calls, as such, but to their content: negative or positive. Violet objected to telephone calls in Hanna's initial school placement, finding them negative and stressful. Rhoda, too, found the calls from Daniel's first school negative, and she kept him home as a result. When Karla received phone calls from her son's school, on the other hand, they were seen as an invitation to come to the school to talk about David's difficulties, and resulted in a positive feeling. As for Laura, when she received phone calls from her son's school, they were neither positive nor negative. She characterized them as prompts to get Shawn to complete unfinished work assignments. In her case, she seemed to perceive them as a necessary tool to get Shawn work, but they also enabled her to remain arm's length from the school, and to provide as much support as she was comfortable with providing.

In general all parents talked about “being heard,” though the context and perception of being heard varied. Yet none of the parents commented on the difficulty of their child’s not hearing them. At the same time they also wanted to listen to the professionals. The parents in this study who believed the school was both listening as well as talking were more satisfied. As well, if the parents felt that they could both listen and tell the school their thoughts, then they were more satisfied with the communication and the relationship they had with their child’s school. Perhaps one of the best examples of this was Lydia, who spoke of her experiences of not being heard and how they impacted her perceptions that her daughter Natalie was not being heard. Being heard meant that schools listened and understood parents’ explanations about their child – about what they and their child needed and who they were.

In summary, this chapter reviewed and analyzed the seven parent interviews by identifying relevant themes that occurred across some or all of the parents’ beliefs and perceptions. Connections to previously cited literature were noted. While the initial intention was to find out how parents perceive medication use for EBD, it is important to probe underlying information from parents about their beliefs, including their own experiences, how they view EBD, and the supports they receive to manage it. By understanding these pieces, we can understand how they arrived at the decision to about using medication for their children.

CHAPTER 5

Conclusions and Recommendations

This study was designed to look at parents' perceptions of medication to treat their children's EBD. The seven parent subjects were asked questions and their initial answers were probed. The complete text of the interview protocol can be found in Appendix B. This chapter begins by summarizing results of the study and outlining its limitations. It then discusses implications of the research for professional development of school personnel and concludes with recommendations for further research.

Summary of Conclusions

The focus of the interviews was parents' reflections on their children's experience with the designation of EBD and specialized supports in their school program. These experiences were the context in which to explore perceptions of medication as an option to treat EBD. Research questions that prompted the interviews with parents included:

- What are the factors that influence parents' acceptance of medication for EBD?
- What are some of the barriers to continued use of medication to treat EBD?
- What is the nature of the relationship between parents and schools where children are funded for EBD, and specifically, for those children treated with medication?
- In what ways has medication helped or hindered their child's behavior?
- In what way, if any, has school impacted parents' beliefs about the behavior of their children?
- Has Appropriate Educational Programming legislation and the process it mandates, helped parents support their children's needs?

Factors that influenced parents' acceptance of medication for EBD included most importantly, their own experience with medication and the beliefs they held about its use for children. Parents were also largely influenced by the degree of difficulty their child experienced socially, emotionally as well as academically in the decision to use medication as a treatment. As well, it seems that for five of the parents interviewed in this study who chose medication to treat EBD, the relationship with the school and the part that it played in the planning for their child helped parent and child to sustain medication as a treatment. Ongoing communication helped them to see what was being done for their child and they were receptive to the school's flexibility in planning for their child.

Barriers to continued use included side effects of the medication but even these seemed to be tolerated in light of the positive effects of medication on behavior. Compliance issues by the older children were mentioned but not prohibitive: the parents who chose medication were positive about its effects and relayed that positive attitude to their child who may have shown reluctance to take it. The parents in this sample who chose medication as an intervention believed it helped their child not only at school but at home as well.

Regarding *the nature of the relationship between parents and schools*, certainly in the case of the two parents whose children were not diagnosed with a mental health disorder and therefore were not prescribed medication, the relationship between the parent and the school was considerably more distant than those parents whose children were prescribed medication. While it is difficult to generalize from the experiences of two parents, one has to wonder why the relationship was strained and what were the respective contributions of parent and school. One possible explanation may be that when

a child with EBD is not receiving medication and has continuing difficulty at school, parents are perceived as not doing all that they can to help their child.

With respect *to ways medication helped or hindered their child's behavior*, the most important finding is that the parents who chose medication as a treatment believed it brought their child's behavior into a range considered more normal for a child of that age. None of these parents indicated that they continued medication without improved behavioral indicators. Interestingly, improved academic performance was not paramount: they only noted improved behavior, relationships and participation in their child, and were eager to build on these improvements.

Finally, regarding *the implementation of Appropriate Educational Planning legislation and the process it mandates regarding inclusion of parents in the school planning*, most of these parents recognized the value of being a part of a team that planned for their child. They wanted to play an active role where they would feel heard. For two, it was their own preferences that led them not to participate as fully as possible. In spite of choosing not to participate however, these parents were adamant in supporting education in general and their child's attendance at school. Thus non-participation did not indicate a de-valuing of school. With the parents participating less, the schools provided alternatives such as copies of applications and planning documents: these were viewed by parents as valuable.

It is telling that there were more parents interested in participating in this research than the researcher had time to interview. Initially, when she was designing the study, the researcher was concerned that the time required for hour-long interviews would limit those able to participate, and that there would not be enough interested parents

volunteering. Instead, there were more than enough, a fact that highlights a need that these parents had to be heard by someone willing to listen about their experiences with a child designated EBD in a school setting and their level of social isolation.

Limitations of the Study

A limitation of this study was that it gathered information only from parents and more specifically, from mothers. There was no effort to talk with the child, with fathers or with school personnel about how they viewed issues of medication and EBD. Validity could have been enhanced by triangulating mothers' opinions with comments from these other people, and even by examining each child's funding application. To some extent, too, additional follow-up interviews with mothers and/or fathers might have added helpful information.

As planned, each mother was interviewed on only one occasion for at most one hour. Initially, in planning the study, the researcher chose to use a single interview to make participation for the parent as easy as possible. As it turned out, however, an additional interview of similar length would have been useful in some cases to check the interpretation of parents' initial comments or to invite further elaboration. Again, triangulation would have enhanced validation. Lastly, as with many qualitative studies, the sample size was small and the transfer of results to other parents of children must be done cautiously. The study serves well, however, for identifying the range of concerns of parents, and for identifying problems about including parents in planning for students with EBD.

Implications for School Staff and Professional Development

The interviews suggest a number of ideas for improving supports for parents of children with EBD. The ideas vary in the ease with which they might be implemented, but are important:

- School personnel need to hear parents: listen to explanations of what their child is going through. Problem solving regarding the struggles parents encounter in trying to support their child's education needs to be a focus in planning meetings.
- Paraprofessional support may need to be more closely examined to see how best it fits with the child's needs and personality. Some children do best with direct support while others may require a more distant yet available model. Alternative styles need to be explored and validated.
- Schools need to allow children with EBD to have safe, private places outside of the classroom to withdraw and to collect themselves in an effort to develop self-control. Staff working with a child may need to explore how this time out is used at home and the meaning it carries in different environments. While educators' philosophy is usually focused on providing an inclusive environment, the parents in this study also stated that their children needed opportunities to retreat in order to prepare themselves to re-connect with classmates and teachers. Withdrawing should not be portrayed as a negative strategy, but as one that will help a child practice moving toward self-regulation.
- Professionals should also understand that if a parent does not participate in school planning meetings it does not mean that they do not value school or education. Instead, it may indicate anxiety for example, or misunderstanding of the process.

Meetings with parents may need to involve fewer people or include pre-meeting information sent to the parent to prepare them for a larger meeting. (Some suggestions about these strategies are included in the *MECY Challenges to Possibilities* document in Appendix E).

- It would be helpful for school divisions to keep statistics of types of mental health disorders (externalizing and internalizing) being funded within the EBD category and the number of children being treated with medication. This information would help not only to understand the nature of the EBD population, but also facilitate providing better service. The information is available from most funding applications and could therefore be collected easily.
- The appropriate provincial authorities should review the process of having parents read and sign the funding document. There should be a clear procedure to ensure informed consent so that parents better understand the funding that their child's school has applied for.
- School divisions should review the process of transition planning with parents as early as possible, to prepare their children for moving into new schools. Reducing parental anxiety would improve support for the child.
- Professionals need to assist parents and school staff with explaining the use of medication and other interventions to children. Providing this help might improve compliance with treatment over the long run.
- Professionals should consider how best to develop group supports for parents of students with EBD as a way of addressing the isolation that was a pervasive theme for these parents.

Future Research

Viewed broadly, the results suggest two directions for further research. One direction is to create more complete descriptive analyses of students in the EBD funding categories. This would help to delineate the types of disabilities and the extent of medication use within the school division, information that eventually influences service delivery and training of school personnel. A second direction is to learn more about the difficulties these children and their parents suffer about “being heard”. A further understanding of the communication among parents, children with EBD and schools or the lack thereof – might suggest how to program for these children more effectively. As in the study reported here, these research directions can further both understanding and improve the quality of service by attending to the complex set of influences in the lives of children who have behavioral difficulties. These children are isolated, struggle to learn, and often need intensive supports – as do their parents.

It is therefore important to look at students and their parents in the actual life contexts in which they are expected to manage. If we can better understand how parents create and support these contexts, we can in turn support their children more effectively. Jensen suggested that chronic illnesses have an impact on parents and that, “...we need to think not only of the efficacy of medical intervention but also *what works best with specific families*” (2002, p. 46). His advice is certainly consistent with the findings of this research study: the parents and children were all unique and wanted first and foremost to “be heard” so that their uniqueness could influence intervention strategies. As this study suggests, inclusion, as a philosophy does not simply apply to the child with EBD in the

classroom; it also means including the parent in planning so that the child is supported in transition to society.

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Appendix A



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APPROVAL CERTIFICATE

10 September 2007

TO: Colleen B. Penner Podaima (Advisor K. Seifert)
Principal Investigator

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2007:058
"Parents' Perceptions of Acceptability of Medication to Treat
Emotional Behavioral Disorders in Children"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Bringing Research to Life

Appendix B

Interview Guide for Parents

- Information regarding the child with the emotional behavioral disorder
 - What type of funding (Level II or III) is your child currently receiving?
 - What is the current grade level your child is in? At what point did your child begin receiving funding for their emotional behavior disorder?
 - Has your child received a diagnosis? What is the diagnosis? Who made this diagnosis?
 - Is there a family history of emotional behavioral disorders?
- Parental understanding of funding for emotional behavioral disorders
 - How is your child's school currently programming for your child?
- Treatment choices for emotional behavioral disorders
 - Is your child currently receiving therapy or help from any agencies outside of school? Which organizations?
 - Is your child currently taking medication? What is this medication for? Who prescribes this medication?
- Perceptions of treatment
 - How did you decide on the treatments you are using to treat your child's emotional behavioral disorder?
 - What experiences do you believe have influenced your decisions regarding treatment?
 - Who supports your choice of treatment?
 - Who do you get support from to help you make your decisions about treatment for your child's emotional behavioral disorder?
- Experiences regarding emotional behavioral disorders
 - Has your child been suspended from school because of their behavior?
 - Are you familiar with other children who have an emotional behavioral disorder?
 - Do you know other parents of children with emotional behavioral disorders?
- Relationship with school
 - What have been some of the positive aspects of how the school personnel have worked with your child? Are there any negative aspects?
 - What has worked well with your child? What would you like to see improved in their programming for your child?
 - What was your own history with school? Was it a positive or negative experience for you?

Appendix C

Appendix D

Parental Consent Form

June, 2007

Research Project Title: Parents' Perceptions of the Acceptability of Medication to Address Emotional Behavioral Disorders

Researcher: Colleen Penner Podaima, M.Ed.

This consent form, a copy of which will be forwarded to you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully:

I am conducting research on the topic of how parents view medication as a treatment option for their child who has emotional behavioral difficulties and has been given funding at school. This research is part of the requirements for a PhD thesis that I am completing in the Faculty of Education. I am also a clinician in the school division but do not work in any of the schools that my research is being conducted in.

If you choose to participate in the interview process, I am requesting that you meet with me for approximately one hour. I will not be interviewing your child or their teacher. If you choose to be interviewed, I would like to tape record the interview. While full anonymity is not possible, every effort will be made to protect your privacy. No names or identifying features would be used when I transcribe the taped interviews into hard copy. I will keep your identity and that of your child completely confidential throughout the project. This means that while your comments may be quoted in the dissertation or study reports, they will not be attributed to you and will not be shared with any school personnel or clinical personnel such as the clinician with whom you and your child are involved. I also ask that you keep confidential your own comments that you might make during the interview. That is, please do not tell others exactly what you say in the interview.

There is no specific cost or benefit to your involvement in this research, though it will take some of your time to participate and you may find it valuable to share some of your thoughts and insights regarding children with Emotional Behavioral Disorders and to reflect upon this topic. I will keep the tapes of our interview in a secure location in my office. A typist, research assistant and I will be the only ones who will have access to this information, which will then be compiled into a thesis that I am presenting to faculty and students at the University of Manitoba. The data from the interviews will be kept for 2 years at which time it will be destroyed. I will also be sharing the results of this research with school division personnel and may publish the results of this research. I will send you a copy of the summary of my findings once I am completed the research if you wish.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in this research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence.

Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. You may contact me, Colleen Podaima, at 669-5643, ext. 245 or my faculty advisor, Dr. Kelvin Seifert, Educational Administration, Foundations and Psychology at 474-9859.

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above named persons or the Human Ethics Secretariat at 474-7122 or email Margaret_bowman@umanitoba.ca. A copy of this consent form will be given to you to keep for your records and reference.

Participant's signature _____

Date _____

I would like a copy of the summary of results: Yes _____ No _____

Address to send summary of results:

Appendix E

Excerpt from: Manitoba Education, Citizenship & Youth. (2001). *Towards Inclusion, From Challenges to Possibilities: Planning for Behavior*. Winnipeg, MB: Author.
<http://www.edu.gov.mb.ca/k12/specedu/beh/pdf/8.pdf>

