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A Phenomenological Study of Parents'
Experience with Interagency Case Planning

by

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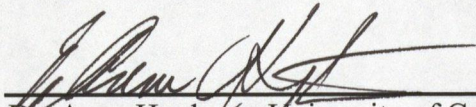
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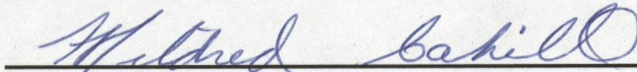
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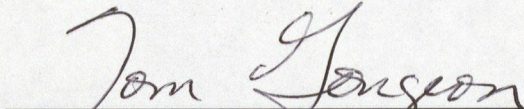
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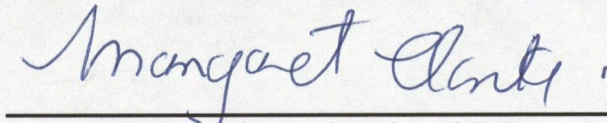
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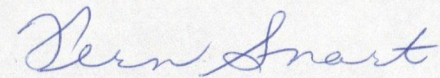
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ABSTRACT

A hermeneutic phenomenological research method was used to examine the question “What is the experience of parents in the interagency case planning model currently used in the province of Newfoundland and Labrador?” To explore this question eight parents of children diagnosed with Obsessive Compulsive Disorder (OCD) who are currently receiving support under this plan participated in the study. The purpose was to gain an understanding of parents’ perspectives of this approach and how it affects collaboration and empowerment. The study will contribute to a broader understanding of this model, and will offer insight to facilitate case planning, teacher training and program development.

Through qualitative data analysis themes emerged in three distinct phases including,
The process

- Having a child with OCD radically alters the interactions of parent and teacher, changing the space that exists between the two from being shared, to negotiated to being contested.
- Parents are disillusioned with a breakdown between policy and practice.
- The model results in a politicization of care.
- The adoption of a game metaphor makes it possible for parents to remain engaged.
- The model sets teachers up for failure.

The Coping

- “Detached Vigilance” to the process occurs where parents become watchful of the system and separated from their emotional reactions to it.
- Parents strategically re-work “the game” to suit their child’s needs
- Privatization of support
- Professional expertise is replaced by parent expertise.
- Parents see teachers as not being accountable

The Outcomes

- Parents discover “power within” during their strategic game playing
- Sensitive pedagogy needs to be nurtured.

These findings expand our understanding of the experiences of parents in collaborative case planning and offer a challenge to educators to remain sensitive to the pedagogical significance of our interactions with families. It explores the space that exists between parents and teachers, defining it as contested space despite a model that articulates collaboration and role parity.

DEDICATION

This work is a testament to the courage, strength and insight of eight mothers who embody the essence of unconditional love and the art of parenting.

A special thank you to my many friends and colleagues, among whom I now count Dr. Nancy Marlett, for their guidance and support throughout this entire process.

Above all others, I thank my partner Robert Power whose love and support, patience and faith is forever reflected in all that I do and who I become. Indeed, it is “double happiness”.

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Chapter One: Introduction and Background

The phenomenon that this project explored was parents' experience with school-based interagency planning meetings for children with exceptionalities. In undertaking this process a group of parents was selected whose children have similar needs and who have considerable experience in collaborating with the school through case planning approaches. The study occurs in the province of Newfoundland and Labrador, where a strong interagency model has been implemented. This first chapter in our process to outline this journey serves to contextualize both the study and the phenomenon being explored by giving a brief introduction to the topic, the researcher, the question being explored, the subjects and, finally, the implications. It serves as the introduction to a journey into the lived-world of a group of parents who inform as much as they challenge us with their insight into what it is like for them to collaborate with the school in attempting to find support for their child.

The Phenomenon

There has recently been significant attention paid to the role of parents in the planning process for their children with increased focus on interagency models of collaboration. This shift is coinciding with a broader re-examination of special education practices and an evolving paradigm of disability. The 1983 release of *A Nation at Risk* (The National Commission on Educational Excellence, 1983) resulted in the school reform movement that has since dominated the educational agenda (Lipsky & Gartner, 1997). The first two phases of this process, improving educational outcomes and redesigning management systems, have brought increased attention to, and criticism of, special educational practices (Hockenbury, Kauffman & Hallahan, 2000; Kauffman,

1994; Kauffman 2000; Zigmond & Baker, 1995). Lipsky and Gartner posit that this criticism hails the third wave of the reform process by calling for a blending of special and regular education into a strengths-based model, within a context of diversity appreciation and inclusive practices. For special education supporters who have lobbied for years to bring the needs of children with disabilities to the educational debate, this attention is as much welcomed as it is feared.

Change is hardly new to the field of special education. Kauffman (1981) writes that the history of special education is a “fascinating and complex story” (p.4) that has both paralleled and reflected the evolving social, anthropological and psychological systems of our history. Nevertheless, what has been more central to contemporary special education is the collaborative decision-making process between home and school. Teachers and parents meet regularly to cooperatively design a support plan based on the identified strengths and needs of the child, often referred to as an Individualized Education Plan (IEP) (Heward, 2000; Winzer, 2002). Legislative provisions for special education placement and planning stipulate informed consent and parental involvement at all levels of decision-making (Brown, 1998; Rothstein, 2000). Tiegerman-Farber and Radziewicz (1998) elaborate on this shared decision-making process, seeing it as the hallmark of effective programs and the heart of special education, especially within the context of inclusive settings. They state:

Just as inclusion cannot be imposed as a social system or model, collaboration must be facilitated as a parent-teacher communication process. Parents and teachers must develop an understanding of each other and work toward a concept model that will work within the school as a reflection of the community.

Collaboration is a learning process. It cannot be achieved at once; healthy relationships are partnerships that develop, grow, and change over time (p.195).

While effective home-school collaboration is held as the ideal in special education, concern has been identified for the reality of this practice (Gable, Korinek & Laycock, 1993; Harry, 1992; Leyser, 1985; Yanok & Derubertis, 1989; Voltz, 1994). Rock (2000) states that the barriers to parental empowerment are complex with “parents entering the process with a distinct disadvantage” (p.35).

Newfoundland and Labrador has a colorful history of special education that reflects global trends from segregation to integration and more recently, to inclusion (Smith, Polloway, Patton and Dowdy, 1998). The province’s model reflects clear provisions for collaborative planning and parental involvement at all levels of decision-making (See Appendix A for definition of parents). While the province uses a language of inclusion, special education continues to be the preferred practice, with specialized teachers delivering support to students in a cascade of placement options. In doing so, an interagency approach to case planning, referred to as an Individual Support Services Plan (ISSP), has been developed as a vehicle for the identification of accommodations as well as the model for delivering such services. It is this model that will be used to explore the perspective of parents in collaborative decision making for their child.

Researcher's Interest

In my eighteen-year career I have attended countless planning meetings in a variety of capacities that included teacher, educational psychologist, counselor, district co-coordinator, principal, and private consultant. I have sat on national committees and review panels, and I have taught collaborative practice at the university level – all fostering a broad perspective and a reflective practice. Collaborative planning and inclusive education are central to my belief structure, anchored as much from my experiences in the community as those within the education system. Core to this belief in collaboration is a pedagogical view of role-parity and strong communication with parents. While Newfoundland has a strong policy on collaboration, my experiences identify a wide variety of beliefs and practices in collaborative decision-making in which parents are often at a disadvantage. In preparing to conduct a phenomenological research project it is important that I disclose my opinions and assumptions about the parents' role in this process. To facilitate a thorough exploration of my experience with collaborative planning I had myself interviewed by a colleague. Appendix B of this document outlines a detailed account of this experience.

My career has evolved through a wide variety of positions that ranged from group home parent, to diverse positions within the school system, to parental advocate and, more recently, to faculty member at Memorial University of Newfoundland. I have run the emotional gamut of personal reactions to my own profession, from pride and enthusiasm to overwhelming frustration and disappointment. Through it all I have remained committed to a philosophy of inclusion that extends far beyond the classroom and school site. Perhaps the frequent changes in my career path have helped with this

commitment, allowing a constant renewal of focus and approach. Nonetheless, this breadth of experience serves me well in my current position as assistant professor. It also affords me the opportunity to question the effectiveness of local practice and frame such within a global context. While Newfoundland and Labrador has a strong policy that reflects the contemporary paradigm of empowerment and collaboration, I am left wondering at the reality of its implementation. My questioning the true experiences of parents in this interagency planning process is well founded in my past and is salient for my future in teacher training.

These concerns are underscored by the fact that the new interagency model used in Newfoundland and Labrador, now in its fifth year of implementation, has not been studied, despite some concern for its effectiveness. A recent review of education in Newfoundland and Labrador identified parental concern for this model. *Supporting Learning: Ministerial Panel on Educational Delivery in the Classroom* (Government of Newfoundland & Labrador, 2000) identified much “confusion and turmoil” (p.23) around both the deployment of services and the planning process for special education. Of particular concern to the panel were the frustrations of these parents and their growing demand for specialized services. One of the numerous panel recommendations was a call for a reassessment of approaches to special education planning with “...particular attention to the responsibilities of parents, teacher, support staff and specialist in an effort to rationalize programming and support” (p.26). Another recommendation called for improved strategies “...for informing parents...” (p.26) in the process of planning and intervention. Given the model’s strong focus on collaboration and parent involvement,

these findings are surprising and raise questions about the true experience of parents in this planning process.

Research Question

Within this context of an interagency approach to planning for special education students (framed by a philosophy of inclusion and a movement towards client empowerment for disability services) lies the rationale for a study on participation. This project will attempt to identify these experiences by exploring collaborative decision-making from the perspective of parents in the province of Newfoundland and Labrador. The ISSP model provides clear procedures for shared decision-making. Legislative provisions are clearly outlined. Special education teachers are trained in the model as well as in the field of exceptionalities. What, then, are the experiences of parents in this process? Do they feel empowered? (See Appendix A for definition of parents, and other terms.)

The study responds to the call for increased research in the area (Dempsey & Foreman, 1997; Harry, 1992; Hockenbury, Kauffman & Hallahan, 2000; Smith, 1990) and builds on previous studies by using a qualitative, phenomenological approach to identify the experiences of parents in their participation in the decision-making process for their children. While the literature supports a move towards interagency planning (Dunst, 1997; Illback, 1997; Raif & Shore, 1993; Stroul, 1995) the study will explore the parents' perspectives of this practice as it is being implemented in the province of Newfoundland and Labrador. If we are indeed moving towards an era of empowerment and self-determination, how are parents experiencing this evolution and how do they construct meaning from their experiences?

The Population

Special education is a broad construct with a diverse population of students with equally diverse needs, ranging from enrichment students to those with severe development disabilities and medically fragile conditions (Heward, 2000; Turnbull, et al. 2002; Winzer, 2002). Not all of the students represented in this spectrum require an individualized plan and not all have, or require, an interagency team approach to their planning. Defining what Marshall and Rossman (1995) refer to as the “shared experiences” of such a diverse group of parents in planning for such students might prove impossible as they, in all likelihood, have experiences as diverse as their children’s needs. Subsequently, this research project focused on a specific group of parents, a group whose children’s needs are significant and who definitely require an interagency team approach to planning. This group consisted of parents of students diagnosed with Obsessive Compulsive Disorder.

Penzel (2000) defines Obsessive Compulsive Disorder (OCD) as an anxiety-based condition occurring along a spectrum of compulsive behaviors and obsessive thoughts. Specific characteristics may be relatively normal to human behavior, however it is the intensity and severity of these characteristics that define it as a medical condition. Prevalence rates are difficult to determine yet it is estimated that between 1 – 2 % of the population is affected. Often more prevalent in adults, approximately 42% are diagnosed before age twenty. Males outnumber females, though frequency evens out in adult years. Penzel goes on to report, “school professionals know little about OCD” (p.180) and that successful management of the child’s condition requires a cooperative team effort, with strong communication with the school staff. Stekette (1999) reports that the student with

OCD “experiences recurrent obsessions and/or compulsions that are severe enough to cause considerable distress and to interfere with the person’s functioning” (p.1).

Treatment requires an interdisciplinary team utilizing a blend of behavior therapy, cognitive therapy and medication (Penzel, 2000; Richter et al., 1998; Stekette, 1999).

Focusing on this population of students provided valued insight into programming for students with significant emotional/behavioral needs, often considered the most challenging in inclusive settings (Kauffman, et al., 1995; Kauffman, 2000; Martin, Lloyd, Kauffman & Coyne, 1995; Schwean, Saklofske, Shatz & Falk, 1996; Taylor, Richards, Goldestein & Schilit, 1997). Turnbull et al. (2002) report that these students comprise approximately 8% of the special education population and yet can monopolize teachers’ energies and resources. Effective collaboration and strong team planning has been identified as being extremely beneficial for students with emotional/behavioral disorders, a concern that is underscored by their intellectual ability to handle the regular curriculum and prior inclusive placement (Harvey, 1996; Guetzole, 1993).

The Implications

The study will inform the local context of inclusive education planning, and the field of disability studies. The ISSP process in Newfoundland, while not studied to date, is considered a model of effective collaboration and team decision-making. This particular study offers a unique view on the effectiveness of interagency case planning within a school context by exploring the balancing between what McDonald (1981) references as three types of policy; *written, stated* and *enacted*.

The study also contributes to an increased awareness among professionals of the parent experience in this planning process and should be particularly useful for policy

makers and teacher training programs. It also lends understanding for parents who have children involved in special education and who are involved in this planning process on an ongoing basis. Van Manen (1997) states that a phenomenological approach holds particular relevance to studies on pedagogy where relationships are essential. He writes “we need to listen to pedagogy so as to be able to act in a better way pedagogically tomorrow” (p.149). This concern for future practice is underscored as we move towards an era of greater empowerment in inclusive education and the broader field of rehabilitation.

Overview of the Study

Chapter One serves as an introduction to the phenomenon under investigation and the rationale for studying it. My background with this phenomenon is introduced, as well as how it gives rise to the research question. The population under investigation is presented and the site for the study is briefly introduced.

Chapter Two provides a review of the literature, as it relates to interagency planning. Given that the phenomenon touches on a variety of themes, this will be fairly extensive. The evolution of our current model of inclusive education planning will be explored, framed within the context of recent criticisms of special education and its management system. The literature on collaborative decision-making within an interagency case planning approach will also be reviewed with a particular focus on previous studies of parental participation in the individualized planning process. Finally, the topic of parental empowerment will be examined, both from the perspective of educational planning and also within the broader context of disability studies and management approaches to rehabilitation.

Chapter Three introduces the reader to the methodology used in this study, including a rationale for a phenomenological orientation in exploring parents' experiences within a pedagogical framework. Issues of participant selection, informed consent, data collection and ethical considerations will be detailed. Discussion will include what the researcher intended to do and how this process of data collection evolved once parents became co-researchers. Particular attention will be given to issues of data analysis and hermeneutic interpretation, as presented by van Manen (1997) and Moustakas (1994).

Chapter Four present a phenomenological rendering of the experiences of the participants, as gathered from the interviews and observations. Every effort has been made to present these experiences in the language and manner in which they were articulated. Where appropriate, descriptions of non-verbal language, which was often powerful during the interviews, are included.

The document concludes with Chapter Five, a synthesis of the common themes that emerge. Implications for practitioners are discussed. The importance of a common understanding of the philosophical underpinnings of the policy is also presented. The chapter concludes with implications for teacher training as well as suggestions for additional study.

Chapter Two: Literature Review

Introduction

This chapter serves as a theoretical backdrop for our journey into the phenomenon of interagency case planning for children with exceptionalities. In preparing to explore this shared experience of parents we must first come to a thorough understanding of the emergence of special education and how it relates to our current paradigm of inclusive education. An examination of the research on the planning process for these children and the emergence of case planning, in particular interagency case planning, will be completed. Finally, previous research on parents' involvement will be reviewed with particular focus on issues of participation, empowerment and power structures. This research project attempts to build on previous research so as to gain a deeper understanding of the phenomenon being explored. The literature review will facilitate this by identifying what is already known and by doing so, will guide our inquiry into the unknown.

Special Education and Inclusion

Special education is a notion born in the evolution of society's changing views of individuals with disabilities. Since requiring schools to accept students with disabilities in the 1950's, best placement concepts have been debated (Friend, Bursuck, & Hutchinson 1998). Moving from Itard's work in the late 1700's with "*The Wild Boy of Aveyron*" (Lane, 1976) to the residential schools for the visually impaired of the 1880s and onwards to our current regular classroom initiatives, special education has a history that is indeed colorful. Smith, Polloway, Patton and Dowdy (1998) summarize this history as having three distinct phases; relative isolation, integration, and our current inclusion

phase. Meyen and Skritic (1995) suggest that special education cannot be separated from the broader context of human rights and has, in retrospect, been one long road towards inclusion.

Society became increasingly concerned with human rights in the years following World War II and by the 1950s and 1960s educational placement based upon minority and/or disability status was hotly debated (Smith, Polloway, Patton & Dowdy, 1998). The desegregation of American schools helped solidify human rights for African-American children and blazed a trail for educational programming for students with disabilities (Friend, Bursuck, & Hutchinson, 1989).

Blatt and Kaplan's 1967 release of *Christmas in Purgatory* provided a graphic illustration of the effects of segregation and fueled the cry for improved services for citizens with developmental disabilities. In many ways it supported what Driedger (1989) refers to as "the last civil rights movement", where parents and citizens effectively lobbied for stronger supports and called for a paradigm shift in disability services. Wolfensberger's (1972) theory of normalization added momentum to this shift in thinking and helped affect improvement in educational services for students with disabilities (Salend, 2001). Prior to this period, the few special education students who were in educational settings were contained in separate programs and classrooms and had limited contact with age-peers or regular school initiatives (Weber, 1994).

The release of *One Million Children*, the final report of The Commission of Emotional and Learning Disorders in Children (CELDIC Report), articulated the growing concern of parents and teachers about the quality of educational programming for children based on a review of services and provision for these children. The report called

for increased integration and improved programming based on individual needs (Smith, Polloway, Patton, Dowdy & Heath, 2001). Three main educational concepts grew out of this report and would go on to contribute to the formation of inclusion. They are:

1. Every child has the right to the education required to realize his or her full potential;
2. The financing of education for all students is the responsibility of the educational authorities; and
3. Students with exceptional learning needs should remain integrated with other students as long as possible (Andrews & Lupart, 2000. p.35).

The anchoring of disability education in legislation was the next step. While the CELDIC report would influence future models of education in Canada, the United States passed legislation to determine its model. While both Canada and the United States give full responsibility to the regions (provinces and states) for passing and implementing educational legislation, federal funding laws in the United States were passed in 1975 to ensure the education of all students: United States Public Law 94-142, “The Education for All Children Act”. This act called for a free and appropriate education for all children in the least restrictive, non-discriminatory environment by using a cascade of delivery models with written individual plans to meet their needs (Salend, 2001). This law has been revised four times and the current version is known as Individuals with Disabilities Act, 1997 (IDEA). Canadian provinces have gradually passed provincial legislation that ensured similar programs and delivery models (Weber, 1994). Indirect federal support

for this has come from the 1982 *Charter of Rights and Freedoms* in the Canadian Constitution that challenges discrimination based on mental or physical disability.

Parents, as leaders in social/educational reform, have demonstrated a growing sense of their legal and social right to be involved in process for some time (Rothstein, 2000). Weber (1994) identifies this growing trend of parental awareness of their legal rights. He states that,

Political activism by parents and other advocacy groups on behalf of students with special needs, had - and continues to have - a powerful effect on the provincial governments ... At the same time, it became an accepted, indeed encouraged, practice among professional educators, especially by the nineteen nineties, to involve parents far more extensively in day-by-day educational decision-making (p.10).

Even though the trend was towards legislative promotion of “equal opportunity” in education, has it resulted in inclusive classrooms? Armstrong, Armstrong and Barton (2000) question the effectiveness of such legislation. They write: “historically, equal opportunities legislation in relation to differing groups and the organizations which exist to protect their rights has developed along separate pathways” (p.6). They posit that this fragmentation shatters protection against discrimination and promotes a paradigm of dependency by focusing on required professional services. Fulcher (1989) shares this concern, viewing policies as politicizing individuals and legitimizing power differentials. She views bureaucratic policy development as a “discursive social practice: we act on the basis of our discourse about an aspect of the social world, such as whether we divide

schoolchildren into those with disabilities and those without, or whether we see all school children, firstly, as pupils” (p.16). She cites McDonald (1981) in defining three types of policy: written, stated, and enacted and cautions that when problems arise, an examination of each form becomes essential.

The last part of the 20th century has clearly witnessed rapid changes in society’s treatment of citizens with disabilities, especially in areas of human rights provisions, residential programs and educational services (Heward, 2000; Weber, 1994). While discrimination continues to exist (Neufeldt & Mathieson, 1995; Rioux, 1984), recent years have seen significant criticism. Hockenbury, Kauffman and Hallahan (2000), organize recent criticisms of special education into seven emergent themes:

1. It is a place [placement option] that should become a service;
 2. It is a separate system but should be an integrated system;
 3. It identifies and stigmatizes students but should be offered without labels;
 4. It has no particularly effective methods and could be replaced by good general education;
 5. It returns few students to general education but should return most;
 6. It has changed incrementally but should be radically reformed;
 7. It is needed now but should not be needed if general education is reformed
- (p.4).

Hockenbury et al. express the hope that, “the negativity of the critics of special education will be replaced by a more accurate appraisal of special education’s past and a more optimistic outlook on its future” (p.10). To this end they outline three lessons to be

learned from these criticisms that can assist in redeveloping special education. They suggest, “(a) constructing a defensible philosophy of special education, (b) providing effective and intensive instruction, and (c) improving the quality of teacher training” (p.4). Fuchs and Fuchs (1995) add to this list by calling for more research into special education and a bridging of “the divide between research and practice” (p.526).

Contemporary special education has been challenged by “inclusion”, a philosophy of community development and educational programming that has tended to dominate discussions in recent years. Crockett and Kauffman (1998) outline that one of the challenges of research and discussion of inclusion is that it is a broad construct with many different definitions and interpretations. Nonetheless, the placement of students with disabilities along a continuum of educational settings (ranging from the regular classroom to a specialized facility) is a practice long established and anchored in legislation (Heward, 2000; Rothstein, 2000 Weber, 1994). This “cascade model” was first proposed by Reynolds (1962) as a means to outline the options of service delivery to students with disabilities. While the practice of inclusion is one option in this model, it is a concept far more complex than placement options, social supports or delivery models might imply. Bloom, Perlmutter, and Burrell (1999) attempt to define it as “ a philosophy that brings students, families, educators, and community members together to create schools and other social institutions based on acceptance, belonging, and community” (cited in Salend, 2001, p.5). While this definition is broad and philosophical in nature it does reflect the belief system that all students, regardless of need, belong in an environment of acceptance and tolerance. Uditsky (1993) builds upon this concept of

acceptance by defining inclusion as the “valued presence and participation of a student with significant disabilities in the regular classroom” (p.86).

Clark, Dyson, Millward and Robson (1999) advocate for still a broader view of inclusion that is linked with diversity education in our global community. O’Brien and O’Brien (1996) support this by calling inclusion a “cultural force for school renewal” (p.31) where the benefits will extend to all students, their teachers and the community at large. Sergiovanni (1994) references this as community building with values of diversity to reflect the social fabric of our communities. Noddings (1992) supports this view of diversity, stressing that schools have a responsibility to promote an “ethic of caring” in our communities via classroom experiences for children.

While inclusion has been argued within a context of human rights and social movements, Touraine (1981) comments that these arguments are “the expression of the collective will...[and]...as agents of liberty, equality, social justice, moral independence, or even as appeals to modernity or to the liberation of new forces in a world of traditions, prejudices and privileges” (cited in Cooper, 1999. p.29). In recent years, writers such as Gale (2000) and Slee (2001) have built upon this notion of inclusion as an issue of liberation and present an argument for social justice. Gale posits that all aspects of social justice have relevance to inclusive education including distributive justice (individual freedom and distribution of goods and services) and retributive justice (the process of attainment of goods and services within a social order). It is, however, the third aspect of social justice, recognitive justice, which he feels bears the most relevance, as it refers to the value and worth that members have within social orders. He states that in order for a society to be a just one, three conditions are required:

1. fostering respect for different social groups through self-identification
 2. opportunities for groups self-development and self-expression, and;
 3. the participation of groups in making decisions that directly affect them
- (p.260).

Gale cites Young (1990) in stating, “Recognitive justice moves beyond an approach to social justice that gives primacy to *having* to one that gives primacy to *doing*”(p.260). Gale stresses that recognitive social justice approaches do more than permit participation in decision-making but add value to “the process that takes account of the interests of all participants or those that serve the interests of dominant groups” (p.264). This links back with what Foucault (1977) discussed in his examinations of the social construct of disability. He identified that one of the strategies used by systems to control subjects and maintain power over them is surveillance, “where via observation and normalising judgments and examinations” (p.195) subjects are individualized and thereby stigmatized as *dis-abled*. Foucault argues that the process of focusing on a student's deficits, through a process of assessment, creates a diagnostic prescriptive model that rationalizes stigmatization and discrimination. Allan (1996), in reflecting on Foucault's work, argues that the individualized nature of special education focuses on the deficits of the child and thereby supports a paradigm of difference. The resultant power and knowledge that professionals gather contribute to a marginalization, impeding the process of inclusion and empowerment.

The intensity of these recent debates, as well as the educational reform process has placed special education at a crossroads (Kauffman, 1994; Kauffman, 1999; Zigmund

and Baker, 1995) and in fact, at a collision with the emerging paradigm of inclusion. While special education evolved from the provision of specialized instruction in a cascade of environments, inclusive education has emerged as a school system based on embracing individual differences within diverse learning environments. Newfoundland and Labrador's ISSP model illustrates this conflict by requiring students to be first identified through a "comprehensive assessment" and categorized as having an exceptionality before being eligible for services designed to treat them as equal (Department of Education, 1999). This study will explore this from the perspective of parents.

Emergence of Case Management

In special education, the IEP process has served as the framework for management approaches to disability services. Emerging from American legislation as an accounting procedure to ensure that funding mechanisms were properly implemented, the IEP grew to be both the model of documenting and accommodating a student's individualized needs. Special Education teachers designed these plans, which detailed the exceptionality of the student, their short and long-term goals and the environment in which such would be delivered. With the emergence and growth of inclusive education the traditional IEP would prove less useful. A shift in focus towards empowering the child and his/her family necessitated a less prescriptive model of care provision. While this was occurring, the school reform movement was calling for a streamlining and sharing of services to contain expenses by shifting towards site-based management (Lipsky & Gartner, 1997).

At the same time, the term “case management” was emerging in the broader context of disability services as the framework to define service coordination and management for adults. This concept arose from the shift from institutionalized provision of care for citizens with handicapping conditions to a community-based approach (Mueser, et al. 1998). While no single model or definition is available for case management, Moxley (1989) offers one widely accepted interpretation of the service. He defines it as, “a designated person or team who organizes, coordinates, and sustains a network of formal and informal supports and activities designed to optimize the functioning and well-being of people with multiple needs” (p.17). Whatever the exact model or definition, it appears that the service provides the basis for definition. Raif and Shore (1993) build on this broader concept of case management by defining the “new” case manager as one who has become essential to care provision and client empowerment. They see case management as serving a variety of functions, within a variety of disciplines, coordinating service delivery via an interagency approach.

While educators were being encouraged to streamline management approaches towards a site-based model and to work towards stronger empowerment of the parent, a similar process was happening in community rehabilitation. The growth of this larger societal trend towards empowerment of the client (Maclean & Marlett, 1995) has underscored the inherent risks in large macro system approaches to client care and favors the establishment of a more client-centered approach with greater sensitivity to the individual’s wishes (Perlmutter & Trist, 1986). This paradigm shift from the traditional clinical approach of client management to one of more social concern (Welch, 1973) was reflected in what Greenleaf (1977) called a “bottom-up model of servant leadership”.

Greenleaf advocated for a new paradigm to replace the traditional bureaucracy of the “top-down bureaucratic” process. Neufeldt (1999) framed this within a context of stronger empowerment of individuals and their families in both the design and delivery of services. Stroul (1995) called for the increased use of multi-agency teams in this planning process. She states:

In order to best meet the needs of children and their families, integrated, multi-agency networks are needed to blend the services provided by mental health, education, child welfare, health, juvenile justice, substance abuse, and other agencies. These components must be interwoven into a coherent system with provisions for joint planning, service development, problem solving, funding, and evaluation of services (p.8).

This gradual shift in thinking and approach reflected an evolving social awareness of the roles that clients play in their own care as well as in their communities (Wofensberger, 1999). While the large institutionalized approach to care provision for citizens with disabilities has been replaced with a stronger community-based service model, daily reality for the client has improved only marginally (Neufeldt, 1999; Worth, 1989). If client-centered approaches to management are to succeed, support and planning are required (Marlett, 1986).

Management in the school system evolved to reflect this call for interagency approaches to case planning. Dunst’s (1997) family-centered approach, as characterized by the following, appeared to capture the beliefs inherent in Canadian schools:

- (a) recognition that families are the primary and principal context for promoting child health and well being;
- (b) respect for family choice and decision-making;
- (c) emphasis on child and family strengths and resources needed for normalized patterns of living;
- (d) family-professional partnerships as the catalyst for matching resources to desired choices and actualized choices; and
- (e) mutual respect between families and professionals as they work together to achieve desired outcomes (p. 77).

Barton and Slee (1999) questioned the effect that this movement has on special education, in particular the creation of a market-driven service system. They fear that a philosophy of inclusion is being lost and social justice is diminishing. Fullan (1993) also raised concern for the loss of social value in this reform process. He states:

Making a difference must be explicitly recast in broader social and moral terms. It must be seen that one cannot make a difference at the interpersonal level unless the problem and solution are enlarged to encompass the conditions that surround teaching... In brief care must be linked to a broader, social public purpose (p.11).

Stroul (1995) added to this concern and cautioned that interagency approaches to care provision for children must be well planned. She writes,

...it is more than a network of service components. Rather it represents a philosophy about the way in which services should be delivered to children and

their families. ...Case management is one of the guiding principles that is considered to be an essential underpinning of the system of care concept and philosophy. The principle holds that case management is needed to ensure that multiple services are delivered in a coordinated manner and that services are adapted to the changing needs of youngsters and their families over time (p.5).

This study will explore the effectiveness of interagency case planning to children from the perspective of parents.

Parent Involvement

Participation

Parental participation is key to any model of service provision, whether based in education or community. Tiegerman-Farber (1995) states, "It is in the best interest of education; its reform, and its success to educate parents and focus their skills as child advocates" (cited in Tiegerman-Farber & Radziewicz, 1998, p.176). Riley (1994) posits that parental involvement in education has been a growing trend with an increased focus on education of parents to facilitate active and effective involvement. The result has been a stronger voice of parents as advocates for the needs of their children. Loxley and Thomas (1997), in an international review of special education policy, found a "consistent development towards the democratization of special education" (p.288) with parents having a larger input into decision-making processes.

Dunst (1997) states, "Participatory involvement items have been described as practices that meaningfully involve people in help-giver/help-receiver exchanges and are most likely to result in positive control appraisals about one's existing and emerging

capabilities” (p. 81). Tiegerman-Farber and Radziewicz (1998) define it as, “a creative partnership” that can be used by teachers, parents and administrators to achieve mutually identified objectives in relation to the needs of exceptional learners. Idol, Paolucci-Whitcomb and Nevin (1986) define it as “an interactive process which enables people with diverse expertise to generate creative solutions to mutually defined problems” (cited in Turnbull et al., 2002, p.94).

Central to collaborative decision-making, especially in special education, is child and parent involvement (Heward, 2000; Turnbull et al., 2002; Winzer, 2002). It is listed as one of the six core principles of the American *Individuals with Disabilities Act* (1997) and is reflected in many of the provincial schools acts of Canada (Weber, 1994). Heward (2000) outlines four reasons for strong parent involvement in this collaborative decision-making process:

1. Families know certain aspects of their children better than anyone else.
2. Families have the greatest vested interest in seeing their child learn.
3. The family is likely to be the only group of adults continually involved with the child’s educational program throughout the entire school career.
4. Families must live with the outcomes of decisions made by educational teams all day, every day (p.119).

Despite this change in approach, there is a difference “between the articulation of the policy and its implementation” (Loxley & Thomas, 1997p.288). Case (2000) polled parents of special education children and found that the “parent-professional relationship

remains one of disparity, with the professional persisting in the expert role” (p.287). Case also concluded that with interagency planning teams this problem was exacerbated by a lack of information sharing and a fragmentation of services. This finding is of particular relevance to a study on parental experience with an interagency model, especially if the next phase of special education is greater empowerment of the child and parent (Smith et al., 1998). Winzer (2002) cautions that collaboration is not an automatic occurrence in the planning process. She identifies numerous factors that can contribute to limiting families’ involvement in the collaborative process including lack of self-confidence, skill deficits, impaired objectivity, and economic considerations. Smith (1990) found that there were differences between the legislated intent of the IEP process and its practice. In a review of studies exploring participation he found that parents assume a passive role of “recipient of information” (p. 9). He calls for a “...vigorous revisitation of the IEP process. A research shift is imperative...” (p.12). Tiegerman-Farber and Radziewicz (1998) add to this by stating, “If collaboration requires parent partnership, then schools are going to have to educate parents to function as equal partners” (p.184). They pose the issue of equality for parents in the planning process for their special needs child, citing that the reality of parental involvement differs from the theory. They posit that,

parents are not viewed as teachers of their children and are not accepted as advocates.... In fact, the very design of schools in terms of hours of instruction presents barriers for working parents [and that] most of the social problems experienced in schools can be traced back to the schism between parents and teachers (p.161).

Turnbull and Turnbull (2001) state, “Too frequently, professionals interact with families in a way that connotes expert power and many parents believe that they can contribute little to educational decision making” (cited in Turnbull et al., 2002, p. 96). Yanok and Derubertis (1989), in a comparative study of regular and special education parental involvement in education, found that legislative provisions had done little to ensure the increased involvement of special education parents.

Turnbull and Turnbull (2001) identify four categories of impediments to parental participation as: psychological, attitudinal, cultural/ideological, and logistical components. Quiroz et al. (1999) add three other categories: communication, menu-driven approaches and “teacher-knows-best mind sets”. Rock (2000) states that the “barriers to parental involvement are complex, numerous, and varied” (p.32). She calls for increased sensitivity by teachers to these factors and for specific strategies to effectively address these issues. Nash (1990) states that in an interagency approach the planning process is crucial to facilitating participation, especially the patterns of communication used during the process. He states that, “On the team, individuals tend to communicate in ways that reinforce power and status differentials. Such power differentials are likely to exist on early intervention teams if family members are perceived as lacking power and influence” (p.322). Raffaele and Knoff (1999) build on this notion of power differentials, especially for parents who are economically or socially disadvantaged. They suggest that schools need to be proactive in addressing this and thereby facilitating true participation.

Studies exploring parental participation in the IEP process are few. Vaughn et al. (1988) found that parents assume a passive and minimal role in the meetings. This finding was consistent with an earlier study by Goldstein et al. (1980) in which it was observed that meetings tend to be short (36 minutes on average) with parents contributing less than 25% of the discourse. In a later study, Able-Boone (1993) found it was usually the child's mother who attended the IEP meeting. Harry et al. (1995) conducted a three-year observational study and identified what they referred to as a token role for parents. They found that parental participation declined over time and their involvement was usually limited to securing signatures for consent purposes.

Dye and Bing (1990) suggest that Sherry Arnstein's (1969) model of citizen participation can be applied to educational decision-making and hierarchical structures to overcome the above deficits. They outline that a shift from the traditional hierarchical model of school systems toward what Arnstein refers to as a collegial model will require the establishment of trust and competence among all stakeholders. Arnstein's theory outlines a metaphoric ladder, or taxonomy of participation where the lowest group of rungs is non-participation, the middle group is token involvement and the highest group represents true power. The ladder itself consists of eight rungs (levels of participation), which include, in order of lowest to highest, "manipulation, therapy, informing, consultation, placation, partnership, delegate power, citizen control" (p.217). Arnstein states,

Obviously, the eight rung ladder is a simplification but it helps to illustrate the point that so many have missed – that there are significant gradations of citizen participation. Knowing these gradations makes it possible to cut through the

hyperbole to understand the increasingly strident demands for participation from the have-nots as well as the gamut of confusing responses from the powerless (p.217).

Empowerment

Dempsey and Foreman (1997) portray empowerment as becoming a more salient theme in education with the increased involvement of parents. They cite Rapport (1980) as first offering a definition of empowerment as “ a process by which people could gain more control over their lives” (p.288). Dempsey and Foreman, in reviewing the literature, offer seven essential components of empowerment: self-efficacy; participation and collaboration; sense of control; meeting personal needs; understanding the environment; personal action; and access to resources.

Dempsey and Foreman are not alone in linking participation and empowerment. Stroul (1995) suggests that a core role of case managers is providing families with the knowledge and the skills to become effective and empowered self-advocates. Donner et al. (1995) support this, calling for greater involvement of parents at all levels of decision-making “and not just token representatives” (p. 34). Dunst (1997), reviewing the literature on strategies that help empower families, outlines a series of factors that include, among others, “...sincere sense of caring, honesty, empathy, active and reflective listening, provision of information...enhancement of knowledge ...acknowledging and supporting client decisions...” (p.80). Dempsey and Foreman (1997) link the concepts of self-efficacy and locus of control with empowerment. Citing the work of Bandura (1994), they stress that in order for people to feel empowered they must believe in (as well as have experience with) gaining control over their lives.

Dempsey and Foreman also cite the work of Rotter (1966) in identifying an internal locus of control as a prerequisite for empowerment. They lend their voice to the call for additional research in the area.

Dunst, Trivette and Deal (1988) suggest that, "...it is not simply the provision of support that promotes parent, family, and child functioning, but the manner in which help is provided that has positive or negative consequences" (p.96). Pedlar et al. (1999) expand on the notion of context and empowerment and link it with a philosophy of inclusion. In a study of adults with disabilities and their experiences with empowerment, they identify that it is not merely a matter of assigning decision-making responsibility to the client, but of permitting individuals to have prominence and respect in their social and political world. They state, "social and political spheres bring the individual into some sort of power relationship with others as he or she struggles for control over resource" (p.101). Their findings indicate that,

empowerment is a natural result of people's lives having texture; and second, that texture arises when the individual finds a secure place and a rich life in the community and is fully accepted there...by contrast, people whose lives lack texture spend almost their entire time in a world that is defined by disability and that is tightly programmed, with little or no individual choice and differentiation (p.103).

Power structures

In examining the effectiveness of management systems as vehicles towards empowerment, an examination of power dynamics within relationships is required.

Solomon (1976) identified this by defining empowerment as, "a process whereby persons

who belong to a stigmatized social category throughout their lives can be assisted to develop and increase skills in the exercise of interpersonal influence and the performance of valued social roles” (p.6). Solomon called for, “identification of the power blocks that contribute to the problems as well as the development and implementation of specific strategies aimed at either reduction of the effects from indirect blocks or the reduction of the operations of direct power blocks” (p.19). Hence, an examination of parents’ perception of “power blocks” is important in understanding their participation.

Researchers have long identified that power differentials between teachers and parents are impediments to participation (Smith, 1990; Rock, 2000; Turnbull & Turnbull, 2001; Yanouk & Derubertis, 1989). Harry (1992) quotes Cherryholme’s definition of power as, “relations among individuals or groups based on social, political, and material asymmetries by which some people are indulged and rewarded and others negatively sanctioned and deprived” (p.127). Suggesting qualitative, intervention-oriented research to explore this, she states:

The current state of discourse in special education reflects an imbalance of power: The difficulties that seem to ‘belong’ to parents, as well as attitudes and behaviors of professionals, contribute to produce a form of discourse in which power is loaded on the side of professionals (p.127).

Illback (1997) states that conflict and disagreement are typical in special education planning. He states, “Unfortunately, program professionals often find themselves in adversarial relationships with parents, rather than finding ways to align with the family and provide support that is empowering”(p.300).

Sontag and Schacht (1994) found that when parents were doubly marginalized by factors such as minority status and low income, their participation in the IEP process declined. O'Brien and O'Brien (1993) suggest that power is a particularly significant theme for people with disabilities. They state, "The person with less power usually sees and feels this difference more clearly than the more powerful person does. People without disabilities take for granted many everyday powers that are privileges in the world of the person with disability" (p.30). Thomson et al. (1997) state "service providers operate from a position of strength when interacting with families" (p.99). MacDonald (1999), discussing power in rehabilitation, states; "If persons with disabilities and their families are to be adequately served, more of the power and more of the money, which is a major source of this power, need to be in their hands" (p.40).

Subsequently, Danforth (1999) suggests that to promote empowerment in the planning process of special education is a first step towards the naming of power as an obstacle. He calls for a greater self-analysis by educators as to how they hold and exert power to the detriment of parents by suggesting a "demystification of the power of professional voices in decision-making process" (p.748).

Bishop (1994) posits that power is a core concept in a society based upon separation, hierarchy and competition. She cites the work of Starhawk (1987) in defining three types of societal power. The first form, "power-over", is based on domination, force and control. The second, "power-with", is based on collaboration, equality and mutually identified goals. The third type, "power-within" is based on one's sense of self and his/her knowledge base. Bishop states the manifestation of power in an

organizational or social structure has significant impacts on both the outcome and the process. She writes:

...in an organization, even one person who needs control and uses the methods of “power-over” can often destroy an experiment in consensus methods. In my experience, when controlling manipulations begin, the other members of the group have to choose among three options. The first choice is to band together in complete unity to resist the person’s attempt to take over. In the second case, one or more members lend resistance, entering into a power-struggle, which in turn demands the use of “power-over” tactics and ends the co-operative nature of the group. The third option is to break up for the time being (p.30-31).

Bishop states it is this third option of breaking-up that is common and, in fact, typical of many structures created with collaboration as a goal. Bishop sees that the dynamics of power-over is reinforced by the bureaucratic nature of organizations. She theorizes that oppression reinforces this separation along divisive lines of race, class, age, sex, economy, etc. She writes, “A world of systems designed to keep people in un-just and unequal positions is held in place by several interrelated expressions of “power-over:” political power, economic power, physical force, and ideological power” (p.36).

Political, economic and ideological powers are of particular relevance to education. Schools are hierarchical institutions with school board officials and administrators at the head (Greenleaf, 1997). Resources, i.e. economic power over which parents and teachers compete, are seen as sacred commodities (Hockenbury, Kauffman & Hallahan, 2000; Kauffman, 1999).

Wartenberg (1990) offers a slightly different theory to examine and define the concept of power. He suggests a “field theory of social power” in which power is viewed as neither a negative nor a positive phenomenon in itself, but rather has the ability to be either positive or negative. He states the field theory of social power construct is worthy of exploration in helping to explain, “why the presence of power constrains the actions of social agents in a way that those agents can challenge and even, under certain circumstances, alter” (Wartenberg, 1990. p.6).

Like Bishop, he divides the construct and shares the view of “power-over”, but instead names “power-to” as the second form. He feels both have a clear place in social phenomena with power-to referencing one’s ability to enact a force that causes a change or an effect, while power-over is a broader construct with broader implications for social interactions. It is this second definitional category of power-over that is central to his theory and to his exploration of social power. It becomes the backdrop for exploring how, “an agent who exercises power over another agent does so by affecting the circumstances within which the other agent acts and makes choices (p. 88)”. Wartenberg calls the agent with the power over another the dominant agent, while the one who has had power exercised over him/her is called the subordinate agent.

He names the following as significant aspects of power in social contexts: actions (both implied and realized); interests and motivations of the agents; the evolving social environment in which it manifests; the relationships that exist between the agents; and the structures and demands that the institution itself imposes on the agents. These are of particular relevance to the ISSP process, where team members change and knowledge is unequal.

Wartenberg divides the manifestation of social power into three types that work collaboratively with one another. He calls these three forms force, coercion and influence. While “force” and “coercion” are viewed as being ineffective, since they are simplistic, transparent and require so much energy, “influence” holds more prominence. Wartenberg feels influence is more significant, since it is subtle yet highly effective. Influence occurs along a continuum of manifestations where the dominant agent gets his/her needs met by controlling communication with the subordinate agent and using behaviors such as persuasion, expertise, and manipulation (cognitive and emotional).

Field theory of social power reflects an interaction of force, coercion and influence within an evolving and dynamic social context. It is this changing field that defines the strength and manifestation of power structures and their impact on participants. Wartenberg uses the analogy of a magnetic field to illustrate his theory, stressing that the strengths of the attractions are really determined by the presence of other agents, the distance between them, their willingness to be influenced and the size and strength of the agents themselves. While some factors may have a larger role in the fields, these factors are constantly evolving as agents come and go, and new alignments are made.

Summary

If a paradigm shift in case management parallels the call for reform in special education in favor of family empowerment, exploration of participation and power in the planning process is a useful undertaking. Newfoundland and Labrador’s ISSP process (Government of Newfoundland and Labrador, 1996) appears reflective of a philosophy of collaborative parental involvement, within a family-centered model of interagency case

planning. This research project will attempt to determine if it is indeed resulting in parental empowerment.

Chapter Three: Methodology

Introduction

This study attempts to add to previous research and facilitate contemporary practice in collaborative decision making for children with exceptionalities. In this chapter, I outline in greater detail the approach used to collect and analyze data, the role of myself as researcher as well as ethical considerations in conducting this project. I begin by offering a rationalization for my choice of a qualitative method to accomplish this task. In doing so, I stand clearly with Berg (2001) who states that qualitative researchers seek to understand the interactions between people and how they make sense out of their surroundings. He goes on to state, “As a result, qualitative techniques allow researchers to share in the understandings and perceptions of others and to explore how people structure and give meaning to their daily lives. Researchers using qualitative techniques examine how people learn about and make sense of themselves and others” (p.7).

Guba and Lincoln (1998) hold that there are many competing paradigms within the qualitative domain as well as an equally broad array of methods. The choice of paradigm and method needs to be explicit so that, “...no inquirer ought to go about the business of inquiry without being clear about just what paradigm informs and guides his or her approach” (p.218). An insight into how personal attitudes and experiences influences choices is also required (LeCompte & Preissle, 1993). Denzin and Lincoln (2000) discuss the personal knowledge and beliefs the researcher brings to the data analysis. They state, “The gendered, multi-culturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) specifies a set of questions

(epistemology) that he or she then examines in specific ways (methodology, analysis)” (p.18). They frame this blend of theory, question and method as “interpretive paradigm” from which data is viewed. “All research is interpretative; it is guided by a set of beliefs and feelings about the world and how it should be understood and studied” (p.19). I have attempted to address this in my bracketing experience.

Kvale (1996), writing about the shift in paradigms in social research, contends there has been a move from a positivist philosophy towards a more pluralistic understanding of the humanities. “These include a postmodern, social construction of reality, hermeneutical interpretations of the meanings of texts, phenomenological descriptions of consciousness, and the dialectical situating of human activity in social and historical contexts” (p.11). Post-modernism moves away from a universality of thought towards a multiple construct, individually defined by action and reaction, within a fluid environment. Kvale (1996) stresses that the emphasis is on the local context, “...on the social linguistic construction of a perspectival reality where knowledge is validated through practice. There is openness to qualitative diversity, to the multiplicity of meanings in local contexts. Knowledge is perspectival, dependent on the viewpoints and values of the investigator” (p.96). Individual experience and the way in which people construct meaning from their lives is given more recognition. Guba and Lincoln (1998) express the view that social construction of meaning,

...can be elicited and refined only through interaction between and among investigator and respondents. These varying constructions are interpreted using conventional hermeneutical techniques, and are compared and contrasted through a dialectical interchange. The final aim is to distill a consensus construction that is

more informed and sophisticated than any of the predecessor constructions (including of course, the etic construction of the investigator (p. 207).

In addressing ontological and epistemological questions that result in a post-modern, constructivism paradigm, the methodological approach deemed most suited to the research question defined by this proposal was phenomenology.

Phenomenology

Schwandt (2000) states, “Phenomenological analysis is principally concerned with understanding how the everyday, intersubjective world is constituted. The aim is to grasp how we come to interpret our own and others’ action as meaningful and to reconstruct the genesis of the objective meanings of action in the intersubjective communication of individuals in the social life-world” (p.192). Grounded by a belief that all knowledge is anchored in human experience, phenomenology is an approach to gathering knowledge by defining experience of the participants and exploring how they interpret it.

Moustakas (1994) identifies that phenomenology was a term first coined in late 18th century philosophy. Early definitions referred to phenomenology as “...knowledge as it appears to consciousnesses, the science of describing what one perceives, senses, and knows in one’s immediate awareness and experience. The process leads to an unfolding of phenomenal consciousness...”(p.26). Van Manen (1997) explores the German influence on phenomenology and references Husserl (1970) in helping form his definition: “Phenomenology is the study of the lifeworld – the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize, or reflect on it” (p.9).

Van Manen goes on to suggest that phenomenology is a particularly useful methodology for research in education as it examines and strengthens practice by recognizing the importance of lived experience in pedagogy. He states, “Pedagogy requires a hermeneutic ability to make interpretative sense of the phenomena of the lifeworld in order to see the pedagogic significance of situations and relations of living with children” (p.2). He outlines an argument for educational research to be guided by pedagogical themes and recognizes phenomenology as being particularly useful in this context. He writes, “The fundamental model of this approach is textual reflection on the lived experiences and practical actions of everyday life with the intent to increase one’s thoughtfulness and practical resourcefulness or tact. Phenomenology describes how one orients to lived experience, hermeneutics describes how one interprets the ‘texts’ of life” (p.4). Given that this study focused on identifying parental perceptions of participation in the ISSP process, a phenomenological approach was well suited where the goal was to “...describe the phenomena as they are lived rather than to give an abstract explanatory account” (Pollio et al., 1997. p.46).

Moustakas (1994) comments on the appropriateness of a phenomenological method for a post-modern and constructivist paradigm. He states that, “the ontological assumption of this tradition is that reality is subjective and there are multiple perspectives of reality as experienced by different people. For this reason, multiple reports of a phenomenon must be gathered in order to understand the underlying invariant structure of a phenomenon” (p.9). Van Manen (1997) adds to this appropriateness by referring to the subject as a “co-researcher” who engages in a dialectic relationship with the researcher to describe his/her experiences. Kvale (1996) articulates the relevance of phenomenology

for examining the meaning people give to their experiences. He writes, “Phenomenology attempts to get beyond immediately experienced meanings, to make the invisible visible” (p.53). In expanding on this belief, Moustakas (1994) outlines nine core themes of phenomenology:

1. Phenomenology focuses on the appearance of things, a return to things just as they are given, removed from everyday routines and biases, from what we are told is true in nature and in the natural world of everyday living.
2. Phenomenology is concerned with wholeness, with examining entities from many sides, angles, and perspectives until a unified vision of the essences of a phenomenon or experience is achieved.
3. Phenomenology seeks meanings from appearances and arrives at essences through intuition and reflection on conscious acts of experiences, leading to ideas, concepts, judgments, and understandings.
4. Phenomenology is committed to descriptions of experiences, not explanations or analyses.
5. Phenomenology is rooted in questions that give a direction and focus to meaning, and in themes that sustain inquiry, awaken further interest and concern, and account for our passionate involvement with whatever is being experienced.
6. Subject and object are integrated – what I see is interwoven with how I see it, with whom I see it, and with whom I am.
7. At all points in an investigation intersubjective reality is part of the process, yet every perception begins with my own sense of what an issue or object or experience is and means.

8. The data of experience, my own thinking, intuiting, reflecting, and judging are regarded as the primary evidence of scientific investigation.
9. The research question that is the focus of and guides an investigation must be carefully constructed, every word deliberately chosen and ordered in such a way that the primary words appear immediately, capture my attention, and guide and direct me in the phenomenological process of seeking, reflecting, and knowing (p.58-59).

Further sections of this chapter will explore these themes more fully.

Selection Procedures

LeCompte and Preissle (1993) state, “Studying any group requires locating it and differentiating it from other groups” (p.61). Such a group, defined by specific parameters set by the researcher, becomes known as a bounded population and thereby becomes the focus of the study. Populations may be either naturally bounded by clearly visible factors, such as geography, or artificially bounded by conceptual traits determined by the researcher. Artificial population are more difficult to define and locate, and therefore requires more stringent identification techniques (LeCompte & Preissle, 1993). This project identified and studied an artificially bounded group, namely eight parents of students who had been diagnosed with Obsessive Compulsive Disorder and had been on an ISSP for at least two years. This time requirement ensured that the parents were familiar with this process by reason of their having attended numerous ISSP meetings, qualifying them as “experts”. Efforts were made to include the mother and father, by attempting to work around scheduling limitations, child-care needs, and transportation. (See Appendix A for Glossary)

In establishing selection procedures for identifying this group I used a criterion-based, unique-case approach. I approached health care agencies that work with this population of students and I encouraged a “word-of-mouth” process, which LeCompte and Preissle (1993) refer to as a snowball or network format. Letters of introduction (See Appendix C) were forwarded to interested parents and consent forms (See Appendix D) were signed. Within a period of two weeks eight participants identified themselves to me, all extremely eager to participate and pleased that research was being completed in the area of OCD. In fact, there was so much interest that I then had to notify referring agencies that all subjects had been selected.

This group of parents proved to be quite diverse with many having professional training and experience with interagency case planning. Three were teachers, well versed in the ISSP model and all employed in the school board where their children were enrolled. One was a social worker who had been trained in the model and who reported having attended “countless” ISSP meetings in a professional capacity. One was a medical doctor, trained in issues of anxiety spectrum disorders which included OCD. This lends an interesting sidebar to the findings. 62% of the participants would be considered professional participants in the ISSP process, with 38% being teachers. These parents were both experienced and informed, and framed their opinions within a context of their personal and professional backgrounds. Table 5.1 illustrates the professional backgrounds of the parents, the different grade levels of their children, as well as their role in this study.

Parent	Career	Child	Interview	Observation	Focus Group
A	Teacher	Intermediate	X	X	
B	Doctor	Elementary	X		X
C	Business - manager	Elementary	X	X	X
D	Business - clerical	Senior high	X		X
E	Teacher	Graduated	X		X
F	Accountant	Senior high	X		
G	Social Worker	Intermediate	X	X	X
H	Teacher	Senior high	X		

Figure 5.1 Parent profiles

All schools were within the same school district, a large school board with a diversity of schools and families. Therefore, permission was also obtained from the Director of the School Board, as per school board policies. To ensure confidentiality, this board has not been named in the final report.

Data Collection

As recommended by Denzin & Lincoln (2000), I used a variety of data collection strategies. They stated, “The combination of multiple methodological practices, empirical materials, perspectives and observers in a single study is best understood, then, as a strategy that adds rigor, breath, complexity, richness, and depth to any inquiry” (p.5). LeCompte and Preissle (1993) suggest researchers “use many kinds of data collection techniques, so that data collected in one way can be used to cross-check the accuracy of data gathered in another way” (p.48). Van Manen (1997) supports multiplicity of strategies and cautions against rigid, predetermined procedures. He suggests a more fluid process of data collection, more sensitive to the needs of the subjects. He writes that phenomenology is guided more by a set of principles than a fixed or pre-selected set of techniques. He names “scholarship” as its true method, in that the researcher is a

“sensitive observer of the subtleties of everyday life, and an avid reader of relevant texts in the human science tradition...” (p.29).

These words proved prophetic as I began the process of data collection. I initially planned to use observations of ISSP meetings and interviews. Three data collection sessions with each parent (or set of parents) were envisioned. The first was to consist of my attending and observing an actual ISSP meeting. My intention was to enter into “the lived-world” of these parents, to provide us with a common experience which would assist them with sharing their experiences. The second session was to be a follow-up individual interview with the parent(s) during which they would be asked to recollect their perceptions of what happened during the ISSP meeting. A third, and final session was to be a second, more in-depth interview, during which I would explore the themes that emerged from preliminary analysis. I quickly discovered that a more flexible plan was required.

While four of the parents eagerly agreed to the initial format, the remaining four proved a challenge. One parent said that she had ceased attending the meetings stating, “I can’t put myself through it anymore”. She was most eager to participate but only through an interview format. Another parent reported a similar observation, stating that there was too much stress in her life to “go through another meeting”. Despite this, she really wanted to be interviewed. A third parent stated that her child had just quit school, while a fourth parent informed me that her child had just graduated. Following much discussion it was agreed to give participants a choice of how to be involved. They could either have me as an observer at a meeting and then interview them, or they could simply participate in direct interview. This flexibility was quickly appreciated by the participants and in the

and five parents joined the “interview only” group while three others participated in the initial observation process. The second interview was changed into a focus group after it was discovered how clear the parents were in their descriptions of the phenomenon. I quickly realized that more in-depth personal interviews would not give me additional information, so a focus group was selected both as an opportunity to bring all these parents together as well as to facilitate triangulation of the findings.

Observations

One concern in phenomenological research is that people’s experiences are fluid and their perceptions of it may not be clear to them. Phenomenological research facilitates both the gaining of perspective on their experiences and the telling of their stories, through the researcher’s role in “...giving an external objective rendering of a subject’s internal subjective world” (Pollio et al. 1997. p.30). Jorgenson (1989) states phenomena may appear different from various perspectives and that, “The more information you have about something from multiple standpoints and sources, the less likely you are to construe it” (p.53). To this end, data collection over time and with varied methods is beneficial.

Once the parents agreed to participate in the observations, I approached the schools to request permission to attend a regularly scheduled ISSP meeting. Given these meetings have to occur at least twice a year (Government of Newfoundland and Labrador, 1996), this was thought to be an easy event to schedule. In fact, I was collecting data in the spring of the year, a time when year-end meetings are regularly scheduled. However, parents quickly pointed out that “this is ISSP season” and getting a meeting time proved challenging. One parent was ill on the day of the scheduled meeting

and had to cancel. When she called to reschedule she was told that the “very earliest” was six weeks time. Subsequently, that parent chose to proceed with an interview only.

During the meetings that I did attend, I was clearly an informed observer, given that I have literally attended hundreds of these meetings in a variety of roles, though I did maintain a participant-as-observer role (LeCompte & Preissle, 1993). Field notes were maintained and analyzed immediately following each meeting to ensure accuracy (Berg, 2001). The observations were not audiotaped in an effort to help participants of the ISSP meeting feel less self-conscious than if their words were recorded, something which might have contaminated the results.

LeCompte and Preissle (1993) acknowledge observation as a primary data collection technique in qualitative research and one which, when used with other forms of data, can assist in providing comprehensive and broad information for researchers. I was guided in my recording by LeCompte and Preissle’s six guidelines: who is participating and their relationship; what is actually happening; where is it happening; when are things occurring; why are things occurring (including the meaning given by participants); and how is the event conducted and order maintained.

Van Manen (1997) refers to this form of data collection as *close observation* where the researcher attempts to enter into the actual lifeworld of the subject with the goal of “... assuming a relation that is as close as possible while retaining a hermeneutic alertness to situations that allow us to constantly step back and reflect on the meaning of those situations” (p.69). Van Manen stresses the researcher must maintain a careful balancing of the researcher and participant roles in order to ensure an opportunity to be reflective without affecting the interactions taking place. The information gathered can

be extremely useful in gaining an appreciation of the lived experiences of the participants. Van Manen writes, “In collecting written descriptions and conversational interviews one looks for the emerging themes after one has gathered the material; in collecting anecdotes one has to recognize what parts of the ‘text’ of daily living are significant for one’s study while it is happening. Sometimes the best anecdotes are re-collected as one tries to make sense of things that somehow seem interesting now, in hindsight” (p.69). To this end, an analysis of the observations led to a follow-up interview where parents’ perceptions were explored.

Interviews

Marshall and Rossman (1999) state that interviewing in phenomenological research, “rests on an assumption that there is a structure and essence to shared experiences that can be narrated. The purpose of this type of interviewing is to describe the meaning of a concept or phenomenon that several individuals share” (p.112). Pollio et al. (1997) add to this notion of a loosely structured interview. They write:

Since the goal of any phenomenological interview is to attain a first-person description of some specified domain of experience, with the course of dialogue largely set by the respondent, the interview begins with few prespecified questions concerning the topic. All questions flow from the dialogue as it unfolds rather than having been determined in advance. It is not uncommon for experiences and issues discussed at an earlier stage of the interview to reappear at a later point (p.30).

Patton (1960) recognizes this format as the first of three types of interviews: the informal conversational interview; the general interview guide; and the standardized open-ended interview. Interviews with parents were relaxed conversations, using, "... a set of issues, developed before the interview takes place, that the interviewer wants to discuss with the respondent" (cited in LeCompte & Preissle, 1993, p.169). Van Manen (1997) states that the conversational interview can serve two purposes: as a mechanism to gather and explore narrative to gain an understanding of the experience, and as a means to facilitate a conversation with the subject about his/her meaning of the experience. He states, "In both uses of the conversational interview it is important to realize that the interview process needs to be disciplined by the fundamental question that prompted the need for the interview in the first place" (p.66).

Kvale (1996) discusses the use of questions to guide this interview and "...obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena" (p.5-6). He states, "the subjects not only answer questions prepared by the expert, but themselves formulate in a dialogue their own conceptions of their lived world" (p.11). Pollio et al. (1997) expound on this use of questioning in a descriptive and facilitative manner. They state, "Dialogue is an aspect of conversation rather than of a question-and-answer session, and no one question is ever critical to an understanding of the overall interview" (p.35). Questions assumed their own flow, order and significance in an effort to facilitate the telling of both their experiences and perceptions of it. Pollio et al. (1997) cite Hagan (1986) in outlining three strategies to assist in making interviews more objective. These include: "i. value-free, objective

questioning, ii. beginning the interview with non-threatening impersonal questions; and iii. non-judgmental responsiveness” (p.32-33).

In this context, the subjects assumed a co-researcher role in leading the conversation that adequately described their experiences (Giorgi, 1985). Each interview began with an open-ended question that allowed the parents to begin at their own pace. The interviews with the parents who did not participate in the observation session all began with the same question: “You are aware that this project is attempting to gather parents’ experiences in attending ISSP meetings. In the last number of days I assume that you have been reflecting on this. What thoughts have come to mind?” The interviews with the parents who did participate in the observations also began with a common question: “Can you describe what it was like to attend that meeting?”

These questions literally opened the flood gates for these parents. While additional clarifying questions were asked, each parent spoke with a candor that was surprising. Themes quickly emerged with remarkable similarity among participants (See Chapter 4). It became apparent that these parents had considerable experience with this phenomenon and spoke of it holistically. The parents used actual events from various ISSP meetings and dealings with their child’s school as examples to contextualize their perception of their participation and how they constructed meaning from it.

Focus group

A focus group was added for a number of reasons. While not in the initial plan, it became apparent that these parents really wanted to relay their experiences and be heard. There was also remarkable similarity in the themes as they emerged from each participant. A focus group offered an opportunity to explore and possibly validate this

similarity. The initial plan for data collection had evolved into two groups of participants which raised some issues for triangulation of findings. A focus group would be an opportunity to bring these parents together, an occasion which would add more depth and texture to the articulation of the shared experience. Parents seemed more interested in sharing ideas than in attending a second personal interview.

Berg (2001) outlines that focus groups "...allow researchers to access the substantive content of verbally expressed views, opinions, experiences and attitudes" (p.114). He goes on to outline a series of "basic ingredients" for organizing a focus group to include: a clearly defined objective; atmosphere and rapport; an aware listening facilitator; structure and direction, but a restrained contribution to the discussion; and, systematic analysis (p. 123-124).

Parents were invited to attend the focus group where the preliminary findings would be presented for further discussion and input. Attendance was voluntary and five of the eight parents attended. Results were presented and discussed, with parents adding to and clarifying the themes. Their input was used as part of the interpretative process.

Data Analysis

Denzin and Lincoln (2000) also speak of the need for a multiplicity of data analysis strategies by stating, "No single method can grasp all of the subtle variations in ongoing human experience. Consequently, qualitative researchers deploy a wide range of interconnected interpretative methods, always seeking better ways to make more understandable the worlds of experience they have studied" (p.19). Finney (2000) calls for rigorous methodology, both in the collection of data and its analysis. She cites Polkinghorne in suggesting "...differentiating between the essential and unessential

elements of the phenomenon” (p. 9). Van Manen (1997) suggests a less rigid approach that is guided by a series of themes to enhance the articulation of the phenomena:

1. turning to a phenomenon that seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes that characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong oriented pedagogical relation to the phenomenon;
6. balancing the research context by considering parts and whole (p.30-31).

Stage One: Bracketting

Phenomenology recognizes that the researcher chooses a topic of interest to him or her which already holds personal meaning. While this insight facilitates the gathering of other perceptions of their lived world, a concern exists for it coloring the findings. One of the first steps in phenomenological research is the setting aside of the researcher's beliefs and experiences “...in order to acquire a clear lens in which to view experiences” (Finney, 2000, p. 7). Often referred to as a process of “bracketing”, the researcher discloses and sets down his/her assumptions at the beginning of the project. These “bracketed” assumptions then provide the backdrop for identification and understanding of the essence of the participant's experiences and perceptions. Moustakas (1994) refers to this process as “*the epoche*” where the researcher enters a “pure internal place, as an open self, ready to embrace life in what it truly offers. From the epoche we are challenged to create new ideas, new feelings, new awarenesses and understandings ...so that we may see with new eyes in a naive and completely open manner” (p.86). Pollio, et

al. (1997) state, “Rather than suspending worldly-knowledge, the interpreter applies a world view such that a phenomenological understanding may emerge. It is a meta-theoretical assumption of existential phenomenology that this worldview allows for first-person description. There is no critical test, however, which proves absolute certainty that a phenomenological understanding is identical to a participant’s lived experience” (p.48).

To facilitate this, I selected a researcher to interview me on my experiences with the ISSP process and my perceptions of parent’s collaboration. I asked a retired faculty member who was well versed in phenomenology, Rogerian counseling and the ISSP process. In fact, this person was also the parent of a young man with significant cognitive challenges who had received special education supports while in school. This session was audiotaped, transcribed, and analyzed (See Appendix B). While the process proved extremely helpful in identifying and articulating my experiences, an added benefit was an increased sensitivity to the process of being interviewed.

Stage Two: Hermeneutic Circle

A second step in data analysis within phenomenology is the *hermeneutic circle*. Pollio, et al., (1997) define this as, “an interpretative procedure in which there is a continuous process of relating a part of the text to the whole of the text...[to overcome]... the linear character of reading by having an interpreter understand earlier portions of the text in relation to latter portions and, conversely, understand latter portions in the context of preceding ones” (p. 49-50). Within this “reductionist” process, the identification of themes and textural/structural descriptions, on an individual and composite level, are important processes. Moustakas (1994) refers to this process as *phenomenological*

reduction where, “the task is that of describing in textural language just what one sees, not only in terms of the external object but also the internal act of consciousness, the experience as such, the rhythm and relationship between phenomenon and self” (p.90)

Giorgi (1985) identifies four steps in this process as:

1. Reading the entire text of the interview to gain a holistic appreciation of it;
2. Re-reading the entire text to identify meaning units;
3. Grouping these meaning units into themes to capture the insight, and;
4. Identification of the structure of the experience, which can be expressed at a number of levels (p.10).

During the interviews I maintained “jot notes” on key terms and concepts so as to ask for clarification. It encouraged me to question, in a manner similar to that used in counselling, until phenomenon was clearly described. It allowed me to engage the participants in a co-analyst role to obtain a deeper understanding of their perceptions of their experience and how they made sense of it. The jot notes were analyzed following each interview and compared to jot notes from previous interviews. There was a great deal of similarity in what the parents were saying and themes began to emerge early in the process.

I also watched for non-verbal cues that could guide my questioning as well as assist with identification of core themes for the parents. It became obvious that this would be an important tool in understanding how these parents detach themselves from the myriad of emotions that this process brings. This helped guide my questions but also helped me frame the language based on these non-verbal cues. To maximize this attentiveness to non-verbal cues I decided to listen to the tape of each interview before transcription,

listening for pauses and matching my jot notes on non-verbal cues to recorded passages. This allowed me to match what I was *hearing* with what I had seen before I began the process of *reading* it. My own experiences with this process, during the bracketing interview, encouraged me to honor my own intuition and hunches and seemed to add an unexpected analytic feature of *feeling* this phenomenon. This multi-sensory, circular approach to identifying the themes proved essential as a precursor to the process of articulating it.

Van Manen suggests four types of emergent themes: *spatiality*, or lived space; *corporeality*, lived body; *temporality*, lived time, and; *relationality*, lived human relations (p.101). He goes on to group these themes as either incidental (not holding particular significance) or essential (the essence of the lived experience).

Stage Three: Thematic Abstraction

This introduces the third step in the analysis process, referred to by Marshall and Rossman (1999) as “structural synthesis”. They explain it as a process of exploring all possible meanings and perspectives so as to “...culminate in a description of the essence of the phenomena and its deep structure” (p.113). Moustakas (1994) refers to this final phase as synthesis of meaning and essences and explains it as “the intuitive integration of the fundamental textural and structural descriptions into a unified statement of the essences of the experience of the phenomenon as a whole” (p.100). Van Manen (1997) expounds on this absence of a final conclusion or punch line by describing phenomenological research as a “poetizing activity”, where interpretation and significance are left, in large part, to the reader.

Language and writing became extremely important in this research project. Van Manen (1997) comments on this link between method and writing as “the art of being sensitive – sensitive to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak” (p.111). He cautions that not only does the researcher need to be sensitive to the language the participants uses to describe their experiences and derive meanings but the researcher must pay careful attention to what is not said, to the silence. He writes, “Silence is not just the absence of speech or language. It is true that in our groping for the right words we sense the limits of our personal language. And in the most profound and eloquent poem it seems that the deep truth of the poem lies just beyond the words, on the other side of language” (p.112). Van Manen summarizes this by stating, “To write phenomenologically is the untiring effort to author a sensitive grasp of being itself – of that which authors us, of that which makes it possible for us to be and speak as parents and teachers, etc., in the first place” (p.132). True synthesis of the experience is a poem that embodies *the telling* as much as *the living*.

Great care was taken to ensure appropriate responsive-reflective writing as being the very core of phenomenological research. Once I had listened to the tapes and had them transcribed for reading, the process of organizing experiences into the core themes was completed. Articulating this into written text proved exhaustive as it entailed a constant revisiting of the transcripts as well as the tapes and the jot notes. I wanted to ensure that what I had heard was what they had said. I also wanted to ensure that the language I used to articulate this was concise and accessible. This became a process of writing sentences and then organizing them into paragraphs, exploring different structures and trying different approaches to articulate what these parents had said.

The focus group proved most helpful in this process of ensuring that what was written was loyal to what had been said. It allowed me to focus on certain aspects, to delve deeper into what they felt were core pieces, as identified by what they shared with one another during the meeting. LeCompte and Preissle (1993) refer to this as “fair-return” for the parents, by ensuring that the language used in the final report is accessible to parents and that the writing style facilitates their interpretation of the true essences that emerged.

Role of Researcher

While the role of the researcher is central to any qualitative approach to research (LeCompte & Marshall, 1993), it has a heightened significance in a phenomenological method (Giorgi, 1985). Eisner (1998) uses the term *connoisseurship* to describe the role of the researcher as an instrument in which the perceptions, observations and interpretations of the subject are central. Pollio et al. (1997) build on this crucial role assigned to the researcher. They state:

The method, or path, that seems natural to attain a proper description of human experience is that of a dialogue in which one member of the dialogic pair, normally called the investigator, assumes a respectful position vis-à-vis the real expert, the subject, or more appropriately, the co-researcher. In this way, a path toward understanding emerges from the common respect and concern of two people committed to exploring the life world of one of them (p.29).

In keeping with this philosophy, this study followed a “participant as observer” model, where significant contact was made with the subjects while an observation stance

was maintained (LeCompte & Preissle, 1993). This created a subjective and interactive interplay with the participants wherein issues of site access, ethics, and researcher conduct become crucial.

“Ascriptive characteristics which cannot be shed, such as sex, age, ethnicity, country of origin, economic status, and social or occupational role shape the questions researchers ask and the kinds of information which informants feel appropriate to pass on to them” (LeCompte & Preissle, 1993, p.121). In this study, the researcher was a middle class male, well-known in special education circles and schools in Newfoundland and Labrador. This was an important consideration in a project exploring issues of participation, as the mere presence of an external person, certainly one seen as having “expert status”, could change the dynamics. It also contributed to the decision to identify the parents as the key informants, given that the researcher is less well known to them. This visibility of the researcher as an “expert” in the field, studying issues of participation in meetings, was a particular concern during the observations of actual meetings where data might be contaminated by my presence.

It had been my experience that most parents in ISSP meetings are mothers and this had been supported by the literature (Rock, 2000; Scanlon, Arick & Phelps, 1981; Yanok & Debubertis, 1989). This was, in fact, the case in this study which raised issues of gender sensitivity, especially in a study of empowerment and participation (Seidman, 1991).

While the issue of my professional recognition and gender sensitivities create what LeCompte and Preissle (1993) refer to as “asymmetry in field relationships”, by clearly defining the researcher’s role and being vigilant about boundary and ethical issues

these factors were identified and dealt with to ensure against contamination of the results. Obtaining appropriate permission from the parents (interviews) and both the school board and school (observations) facilitated site access. By giving the parents the power of voluntary participation and how to be involved, a greater symmetry in the relationship was promoted. Seidman (1991) states equity in relationships is a goal of good qualitative research but one that is never fully realized. “Striving for equity is not only an ethical imperative; it is a methodological one. An equitable process is the foundation for the trust necessary for participants to be willing to share their experience with an interviewer” (p.84).

Ethical Considerations

Issues of symmetry and boundaries introduced the concern for ethics. Permission was received from the ethics committee of the University of Calgary, which stipulated that consent letters identify any risk factors (See Appendix C and D). While prior identification of these issues contributed to the design of the study, additional concerns of vulnerability, risk and informed consent were also important (LeCompte & Preissle, 1993). Marshall and Rossman (1999) outlined that researchers have to be sensitive to these issues when conducting research and therefore must center their work on the needs and conveniences of the participants. By ensuring informed, written consent the researcher established trust with the subjects and created a relationship as symmetrical as possible. Open-ended, structured questions permitted subjects to answer in ways with which they were comfortable. Each interview assumed a relaxed, focused tone that began with non-personal questions and moved towards more focused discussion of the questions. Vigilance to affect and non-verbal cues were also used to help ensure this

relaxed tone. The researcher's formal training as well as seven years experience as a personal counsellor helped in establishing rapport and ensured against moving at a pace that overwhelmed the subjects. Seidman (1991) discusses the need to establish rapport, while avoiding a therapeutic relationship. "The interviewing relationship must be marked by respect, interest, attention and good manners on the part of the interviewer. The interviewer must be constantly alert to what is appropriate to the situation" (p.74). Use of an audiotape recorder permitted the interviewer to attend to the needs and tone of the interview more closely, making it necessary to write only jot notes. Subjects were informed that confidentiality was fully guaranteed and that names would not be used in recording or reporting information. To help facilitate this confidentiality, direct quotes, though taken from each of the parents were not coded to specific individuals in the final text and are separated only by italics and paragraph.

Summary

I selected phenomenology as the method to identify parents' experiences with interagency case planning meetings for their children because I felt that this approach would best articulate the essence of their experiences and, within a post-modern, constructivist paradigm, illustrate how they derive meaning from this process. Van Manen's (1997) hermeneutic approach to phenomenological inquiry facilitated this and helped ensure that the findings would contribute to improved pedagogy in the field of special education.

My own experiences, diverse that they are, served as the springboard for me to share the "lived experiences" of these parents. My training as a counsellor as well as my sensitivity to the realities of home life for citizens with disabilities quickly became the

common ground that allowed me to hear and articulate the essence of parents' perspectives. While attending the ISSP meeting helped ensure a diverse approach to data collection, I underestimated the intensity of these parents' experiences and their need to voice them. Each parent spoke with candor and an apparent eagerness to be heard.

This methodology, matched by the parents' eagerness to invite me into this shared experience, facilitated the emergence of themes, which were then analyzed through a rigorous recursive writing process. From individual interviews, observations at group meetings, examination of jot notes, and listening to transcribed tapes, the essence of this phenomenon began to emerge. The focus group was my first introduction to the blending of lone voices, these single stories, into a group voice. What surfaces is, what van Manen (1997) refers to as an "...incantative, evocative speaking, a primal telling..." (p.13) of this shared phenomenon.

Chapter Four: Articulating the Experiences

Introduction

How do parents experience this phenomenon of individualized planning and how do they derive meaning from it? Here we enter into the space that exists between parenting and teaching where the process of negotiating support for children occurs. Here philosophy and practice meld and the reality of educational policy becomes manifest. What is the nature of this space? Is it shared or contested, denied or acknowledged, and is dwelling here hindered or facilitated by the procedures outlined in Newfoundland and Labrador's ISSP process? How does this planning process alter the natural interactions between parents and teachers and what impact does it have on their perceptions of the school system? Parents serve as our guides in this study, assisting us in traveling into this lived-world with articulate and emotional language. Their descriptions of the ISSP process become trail markers that offer a deeper understanding of the nature of this space by illuminating the essence of interagency case planning for their children.

These parents, all mothers, were both articulate and eager to share their stories. They were quick to discuss their experiences and describe what it is like to participate in the ISSP process. Words flowed with ease, offering insight into their wealth of awareness of this model of planning. They analyzed practice, named policy, knew the participants and shared their history. They spoke with passion and determination about what it is like to collaborate with the school in supporting a challenging child. They were frank about the complexities of OCD, about the confusion and turmoil caused and about the obstacles they encounter in trying to convince others to support their child. Where possible, the words of these mothers are selected as thematic representations, taken from each of these

parents. Coded identities are not used in order to facilitate confidentiality. In doing so, language becomes shared, experiences are identified and a commonality of understanding quickly emerges to form a roadmap into the essence of this phenomenon.

In listening to these mothers we quickly discover that this space into which we are traveling is marked by a kind of aloneness where company is appreciated and experiences await sharing. Not only do we gain insights into parents' perceptions of the ISSP process but we also gain a greater understanding of this nebulous ground upon which parents and teachers interact.

We begin this chapter with an exploration of the process of educational planning, beginning with the realization that their child has become a "special needs child". These parents walk us through the subtle changes that begin to emerge in their relationship with their child's teacher. They articulate the realizations that accompany their immersion into this new world of parent/teacher interactions and they tell how they begin the process of coping, of accessing supports and of attempting to make sense of their experiences. In understanding the child's behavior and in supporting his/her development, what was once a routine school experience is now marked by a new language, by different participants and by the application of unfamiliar policies and procedures designed to help the child function. Finally, we arrive at the outcome – the lessons learned by their experiences and the skills they have acquired. As we traverse through this lived-world of realizations about this shared phenomenon, themes emerge in three stages – the process, the coping and the outcomes, and are left embedded in the text, serving as subtle trailblazers of insight into these parents' experience with interagency case planning.

The Process

These parents did not spend much time discussing their school experiences before OCD manifested. They began with their initial realizations of the magnitude of change that accompanied this diagnosis of OCD, their initial hope for the ISSP policy and their impressions of it as their realities became distinct from the rhetoric. We experience, as they did, the identification of a game metaphor to describe this collaborative process and their growing disillusionment and detachment from the ISSP model. One mother exemplifies this by beginning her story in a way that resembles a flashback, where the film's narrator transports the audience back to where the story first began....

Sometimes, when I think back on it, I wonder if it wasn't all a dream, if we actually lived through it. I have a file in the back of a closet that I don't want to look at but I don't want to throw out either. When I stop to think about some of the experiences we had because of his condition...you almost forget they happened but then you realize that they did...how bizarre they were, yet you lived through it.

Newfoundland and Labrador's ISSP process stipulates that once a child is identified with special needs, as determined through a comprehensive assessment, s/he can enter the collaborative process of interagency team planning at any of three points. This can happen at birth, in the years before they begin school, or at any point after school has started. The parents in this study had their children enter the school system as "regular" children, attending classes and interacting with peers and teachers appropriately. They did not require individualized attention or supports and, as a result, parent interaction

with the school was routine. The child was moving through the curriculum relatively unnoticed in terms of cognitive ability or need. There was a commonality of understanding of the child's needs, and expectations for care and support were quietly assumed. In fact, parenting and teaching seemed to compliment one another with a sharing of the space between the two. All this changed as the child began to present with challenges.

Despite this history of ease, the manifestation of OCD results in the child becoming more visible, with declines in scholastic achievement and challenges in social functioning. Obsessive thoughts and compulsive behaviors interfere with learning and challenge the ability to function in the regular class. This change often happens relatively quickly with an escalation in the child's behavior, in turn resulting in a referral to the health care system. This results in a medical diagnosis that has repercussions for the school program, entitling the child to supports and accommodations to keep the child in a class with his/her peers.

As this happens, the previously routine interaction between parent and teacher begins to change. Parents discover that the teacher's ability to meet his/her needs can no longer be quietly assumed. While cognitively able to attain the curriculum, the behavior that the child exhibits and the stress that the accompanying obsessions bring, require extra attention, a degree of individualized help, and a level of understanding that the classroom teacher reports not to have. The parent looks to the teacher for professional understanding and empathy while the teacher looks back to the parent to get the child under control. The stress level of the teacher mirrors that of the parent and the limitations of both, individually and collectively, become apparent.

The vice-principal called about my son's behavior and said, "I don't know what I'm going to do with him, I just don't know! He got me drove off my head. He has me drove nuts!" I told my husband about the call and he said, "Finally, they understand. Now tell him that we have the child 24 hours a day, 7 days a week. How does he think we feel?"

Parents begin to realize that the help and support that their child requires may not be automatically available. In attempting to explain their child's functioning they realize that the process of articulating the child's needs more closely resembles one of negotiating for understanding and support. Parents begin to discover that there is a difference between what they perceive their child to need and what the child will actually receive. Differing perspectives, conflicting opinions, limited teacher time and lack of knowledge complicate the system's ability to implement individualized help and support this vulnerable child. The lack of understanding and support that parents feel in trying to secure help for their child escalates their stress level while the challenging behavior of the child raises teacher stress. The once amicable relationship between parent and teacher is now compromised.

The ISSP process seems to promise a vehicle to resolve this conflict and to develop effective supports for both parent and teacher. Initial explanations of this individualized planning procedure, the available support services and the approaches to be taken, result in parents developing a positive impression that the school is prepared and able to help their child. As a result, they enter the process hopeful for positive outcomes, encouraged by the language of a policy that outlines role parity, open communication, prioritization of concern and the establishment of a caring environment. They view the written policy

as being strong and reflective of their needs. They agree that all service providers should help develop a common plan, implement it and monitor its success. Parents want to be treated as equals in decision-making and have input into their child's program.

Early in the planning process however, they begin to suspect a difference between what is articulated in the policy and what actually happens. Being new to the process and worried for their child, initial impressions impact strongly on parents. While they are impressed with what the policy says and the planning process that it outlines, parents are surprised to encounter obstacles to its implementation. They discover that teachers are slow to return telephone calls and that they have to wait for the help and support that they are promised. *I've waited months to get a meeting and It's hard even to get a teacher on the telephone.* They discover that meetings are extremely difficult to schedule and, once held, are inefficient, disorganized, and are not child focused. Constant interruptions, excuses, and a focus on problems overshadow strengths and make parents feel confused, distracted and dismayed by what they begin to suspect is tokenism.

These descriptions were validated in the meetings that were observed in this study. Entering into these meetings and sharing the experience with parents allowed me a window into their world, a chance to examine the planning process from an objective vantage point. One such meeting occurred in late May, 2002.....

"Mark" is in Grade 7 at a large intermediate school. His mother arrived at the school at 1:00 for the year-end ISSP meeting and was told to wait in the hallway outside the main office. As the students hurried to class, Mark and a few of his friends saw her. The friends waved hello, while Mark attempted to ignore her, obviously embarrassed by

her presence. At 1:10 the counsellor came and apologized for the late start. She then accompanied her to the counseling office where she sat at the long table. Several students came in to see the counsellor and then left. The special education teacher arrived and explained that the others would be late. At approximately 1:20 someone asked whether the principal and educational psychologist would attend. The counsellor stated that they shouldn't wait for them and suggested that the meeting begin. There was no agenda and a chairperson wasn't identified. The educational psychologist arrived at 1:30, apologizing for her lateness, and immediately started circulating forms for members to sign. Members signed the forms without reading them or asking what they were signing. The assistant principal arrived at 1:35, offering no explanation or apology. Seven minutes after arriving, his cell phone rang and he left. Five minutes later he returned for three minutes and then announced that, *There is no real need to have me here*, and left again. The telephone in the office rang twice and was answered each time by the counsellor. There were four knocks on the door, all of which were answered and two of which took the counsellor away for several minutes. There were four announcements made (and repeated) over the school's PA system. Forty-five minutes into the meeting the special education teacher decided that she should go and "cover" for the other teachers to come and report individually. Two teachers came in separately for less than 5 minutes each. They reported the areas in which the child was struggling and then left without having discussed any strategies to help him. At exactly 2:00 the remaining participants announced that they had to go. The counsellor stated that she would *get the minutes typed and send them out, or as I like to refer to them: the cover-your-ass minutes*.

Although the experiences in this particular meeting seemed rather extreme, parents described similar occurrences as being routine. Following the meeting, Mark's mother commented, *You get completely used to it. You learn to become accustomed to it pretty fast because it certainly doesn't change.* Other parents offered insights into how they derived meaning from this.

It's like beating your head against the wall, trying to set up a meeting, trying to get the right people at the meeting and having to explain over and over and over again what her problems are. They would be up and down like yo-yo's, with other teachers coming and going and the door opening on to the hallway with all her friends out there peeking in. The PA would be coming on and off. They would always be hurrying in or out and their attention was divided in a hundred different ways – they didn't have the time to care. I'd be sitting there wondering, "What the hell am I doing in the middle of this mesmerizing circus?" knowing full well that I had no choice because there was nowhere else to go. They have all the terminology, words and phrases that they learned out of a manual but when you are in there you can see the vacant looks and the constant glances at their watches. You are always being shooed out the door. I've waited four months to get meetings.

The meetings do much more than merely introduce the parents to the pragmatics of special education. They offer a deeper explanation of this new process of negotiating care and support for their child. The meetings become a powerful illustration to the parents of the changes that have occurred as a result of having their child identified with

OCD. Finding themselves in the middle of this new ISSP planning process underlines a clear distinction between parenting a “regular” child and parenting one with an exceptionality. Assumptions no longer exist and negotiating for clarity results in very little common ground remaining between parent and teacher.

In rationalizing their participation in this process, in spite of being disappointed with its realities, parents use the metaphor of game playing. They see the process as being composed of *sides* that are heavily stacked against them. Attending these meetings becomes a process of facing a strong opponent in this game field. Naming the process as *game playing* allows parents to subtly express that they are the opponents in a charade. Thrown into this complex game and facing this formidable team, parents see themselves as the outsiders, as the “other”. They soon learn that they must be vigilant to learn the rules and the plays.

The seriousness is totally beyond them. Last year, I didn't get my first meeting until January and then they said, “We are really sorry, but we are really busy and you know that the squeaky wheel gets the oil so we advise you to start calling earlier next year”. I sat there flabbergasted that they would be so blatant about it and thought, what a game, what a game, how so un-serious these people take this to be.

This metaphor of “game playing” does much more than describe their growing realization that there is a nexus between intended approach and enacted practice. It also affords parents hope. As far as they are concerned they are engaged in the only game in town, and at least see the possibility of winning support for their child. The game

metaphor allows them to both honor their growing realizations and insulate themselves against their emotions. Desperate for help, they attempt to try and make the game work for them as best they can, amid challenging players and rules.

It's a game that you will never win because the teams are stacked so strong against you and they have so little to lose by playing by unfair rules. You know that, but you can't really acknowledge it because you lose your energy and you really need your energy. So you keep playing, hoping against hope that you can stay at the game long enough for the child to get an education. And any emotional/financial/familial cost you stay as silent as possible about.

The sad part is that it is not a group of people working together to help a child, but a group of players in this delusional game. You go in to join the game to fight for something that he should have anyway. You really have to tread carefully. I'm going in to get help but I have to be very careful to do it this way, and make sure that I don't act like I know too much. And I have to smile at this teacher and hide my irritation and I have to watch the clock because I only have a few minutes ...Then you come out of it saying that I should have said this and I should have said that...it's absolutely exhausting. And then it hits you that nothing is going to happen anyway but you are so desperate that you had to try.

This early realization that the meeting process does not result in recognition of need or increased support is quickly matched by a pronounced absence of follow-through on those supports that do get identified. Despite attendance at the meeting and participating

in playing the game, a clear breakdown occurs between this newly developed plan and the consistency of teachers' implementation of it. Having the plan implemented becomes the chief source of parental frustration, resulting in numerous phone calls and school visits. Decisions made in the meeting are seen as paying *lip-service* to *token care and support*.

I was told that there would be accommodations and there never are. It's my understanding in the meeting that he is going to get help and he never does after the meeting ends...Initially, you think it's going to make a difference but after a while you realize that it isn't, that nothing will change.

Parents' growing disillusionment is heightened by the promises inherent in the language that reflects a political paradigm of shared decision-making, role parity and care provision. They frame this politicization of care as a sincere recognition of the legitimacy and severity of their child's needs. Parents are disappointed, yet they must continue to play the game. They become cynical about the language of a policy that articulates something radically different than they experience. They interpret the process as one that articulates procedures to *care for* children yet fails to ensure that the child, or the family, feel *cared about*. While the language of the policy frames a model which is built upon care, parents seldom see caring displayed in their child's daily school experiences or in how they are treated. The process is seen as politicizing an image of care that covers an absence of it.

The ISSP meeting is not really doing what it is meant to do. It is an intimidating process where they will pay homage to you but they aren't going to follow through.

They will meet with you and do the token thing but they will not follow through with what he needs and the child falls through the cracks. They say, "What would you like to see done for your child?" and then the counsellor comes up with a list of accommodations that they could use. It is all so superficial. They act as if they understand. It's like the great sale you see in the Sears brochures. The big headlines read great but the small print tells a different story. "We are going to do this for your child." But then the small print reads, "If we can". "We're going to talk the great talk but don't expect us to walk the great walk".

As disillusionment grows, the ISSP is seen as rhetoric, focusing on terminology, forms and procedures. Parents, as well as teachers, refer to the plethora of documentation as *covering your ass*, in which they follow the politically correct process knowing that there is little expectation of implementation. Parents see teachers as being oblivious to the rhetoric of their profession. *There are so many forms that even teachers get lost.* Teachers are not seen as being willfully neglectful of providing care but rather as players in a system that cannot deliver what is promised. Parents recognize the irony in a model that stipulates that the lone classroom teacher has to deliver supports that a team of people is required to develop.

The perspective of teachers is introduced in this study because three of the parents were also teachers. Speaking from a dual perspective, they verbalized the irony and the conflict that is inherent in the implementation of the ISSP. Interestingly, this "double view" does not bring a common perspective, but rather a separation of understandings. As teachers, these parents articulate the struggle to deliver care in a system that

overwhelms. As parents, they voice frustration with the absence of support for their child. The first priority of parents, regardless of their profession, is to “parent”. Seeing the model as creating a platform for conflict, and seeing teachers as having to become “blind” players in this system, these parents use this additional vantage to allow them a heightened awareness of the game.

Being a teacher myself I know their frustrations. Perhaps if I weren't in the system I wouldn't be as understanding of some of the things that went on but it put me into a better position. I knew that things weren't going to be done just because someone said they would or just because I asked. I had to politely insist on things each year. I had to make it my business to go in and meet every teacher and get known myself. I knew that despite everyone's best intentions he would get lost in the system that I had to keep pushing for what he needed. Knowing how the system ran really helped me. I knew the game so I played it better.

In a sense, these mothers who were also teachers come to a faster realization than the other parents that little will be done. With this realization they are able to become independent and use their own strengths to move into the process of coping.

There can't be follow-through because the teachers don't have time to absorb it, they have so much else on their plates. So we haven't looked for much follow-through because we haven't asked for a lot, except understanding, and we never really got that.

Anger and fear get channeled toward the only person to whom they have access, their child's teacher. While they acknowledge that caring teachers exist, and that many make the effort, they do not believe that teachers realize how the child suffers from such a nexus of practice. Transitioning from having a typical child in the school system to being in the midst of the ISSP process has radically changed the dynamics between parents and teachers. They move from a common understanding and a shared space in the process of the child's education, to being on different "sides" on a game field. Although parents may understand the inherent challenges that OCD brings, their frustration with the ISSP process, combined with their desperation to help their child, prevents much empathy for the struggle of teachers. Parents can appreciate that their child is challenging. Even so, they remain frustrated by how little the system is seen as caring about their child.

People's time is precious and getting a group of people together is next to an impossible task, and from a teacher's perspective I can understand that. But from a mother's perspective there is so much you feel like you need to share before something bad happens. It gets so frustrating, teachers don't know, they don't understand...their knowledge is so limited, they don't see the whole picture. Their expectations are so set and they want to deal with all children the same way with the same set of approaches.

Parents see themselves as having to engage in a process of emotional separation from these painful realities so that they can help their child cope. They see teachers as being engaged in a similar process so that they, too, can cope. Any opportunity for

commonality of experience and perspective, once typical of their interactions, becomes lost in the process of negotiation and the game playing that the ISSP model creates. Ironically, a process designed to bring people together results in separations that create fractures in which empathy and concern become lost. These parents question the priority system of policy makers in creating a model that, regardless of why, clearly results in their child being lost and teachers being undermined in their role.

The worst experience was at the Grade Nine graduation ceremony, which they were still holding in the church at that point. They had the program typed with the graduating class list on the back. We were sitting there that Sunday morning with all the other families and I was reading through the class list, thinking that everything was so well done and it was all so very nice. I then noticed that his name wasn't on the list, that he wasn't included with the graduating class. That's when I found out that he had not passed his math and would have to go to summer school. That's when it hit me: He doesn't fit. He's not one of them. He doesn't belong. I can still cry over that. To go from a point of celebration that he made it to such a realization. The same thing happened in Grade Twelve. By then he was so isolated that he had no idea what was happening around graduation. How could he – he had no friends so he didn't go. He didn't even have the graduation pictures taken. He was so lost in the system by then – the one thing that I fought not to happen.

The Coping

How, then, do these mothers cope? How do they handle the realization that this process in which they have found themselves immersed does not deliver on its promises?

As outsiders they discover a profound sense of aloneness, stemming from the realization that the child is different, that s/he does not fit the system, and that the system does not offer thoughtful attentiveness to his/her needs. The degree of vulnerability that this isolation fosters can only be partially acknowledged. It remains silenced, in part because no one in the system can afford to hear it, and in part because no one can afford to speak it. Parents must budget their energies to help the child, while they see teachers as being so mired in the process that they are deafened to the absence of voice. Parent frustration is evident, though never named; their fear is palatable, though never validated; their disappointment is visible, though never acknowledged.

What we discover in attempting to answer these questions is that what unites these parents is not having a child with a similar condition but their actual ability to remain focused on coping. These parents quickly realize that the child's obsessions and/or compulsive behaviors continuously evolve. Parenting a child with OCD requires that you focus not on the condition but on responding to it, of coping with it, and of continually trying to support the child. This ability to stay aware of process becomes essential as parents begin to try and make this system work for them. We discover how they create a privatized support system and begin the process of empowering themselves with expertise, which they then share with the school. We also discover that the most important rule of this second sub-game is never acknowledging that it is being played.

In looking at how these parents maintain their focus on coping we discover that they use the game metaphor to their advantage. Finding themselves in the middle of a game field forces these parents to elevate their functioning into another dimension. It is as if they stop playing on the two-dimensional game board and lift themselves into a three-

dimensional process, where there are two games happening at once. In exploring this, we learn that one game is about strategically operating around these limitations to create support for their child.

You bargain all the time: when to get upset, how upset to get, what to name, what to ignore, what to settle for – knowing full well that there's more coming. It's like you budget your strength and energy for the bigger battles, which are coming...

Sometimes you want to bang your head against the wall. Sometimes you want to crawl away and cry. Sometimes you have this deep sense of hopelessness that you know that they are going to do nothing. That's when you have to give yourself an extra pep talk so that you can get to the next station.

Understanding that aloneness and in being “the other” allows them to identify that this lack of understanding and support for their child is not exclusive to the school system but extends into the immediate and extended family as well. Partners, friends and siblings, unable to understand the complexities of the condition, become lost in knowing how to help.

He was involved in all the normal childhood activities but eventually he dropped out of each of them because it took so much effort to stay. Then the weight gain came from the medications and he dropped everything else, or they dropped him from the sports teams. He would try so hard to reach out to friends and nothing would come back. In Grade Eight a part of his ritual was to call the same four boys every single weekend. For six straight months he did this and they never once called back. The phone would ring and he would jump, only to be devastated when it wasn't for him.

Finally it came to the point when we had to say... “There’s no point in calling anymore”

Her father doesn’t understand, which leaves me on my own to help her. His statement was “All she needs is a good kick in the arse”. When he found out that I was also diagnosed with OCD he said, “I’d rather you had cancer. At least everyone would understand that”.

Parents do not get mired in this loneliness but re-channel their energy into determination and persistence. As a result, they struggle to make the process work for them by being ever vigilant to procedures and strategic in their participation. In beginning their use of strategy, parents realize that they have to become good at holding back their tears, compartmentalizing their experiences and focusing on immediate challenges. Emotions, frustrations and fears are forced to the side so that caring for their child stays central. This forced detachment from their sense of loneliness and emotional burden of *playing the game* is, ironically, facilitated by their never being asked how they are doing or what they think of the process. *It’s amazing but in all the meetings that I’ve had in the past ten years no one ever asked what I thought of it or how I was feeling.* Their aloneness insulates them from having to acknowledge the game, the personal price of playing it, as well as the disappointment and anger that accompanies the breakdown in support. They become so mired in daily battles that they can’t afford the luxury of looking into the future and facing any fears that reside therein. Emotional detachment becomes as much a result of the process as it is a survival tool for coping with it. Parents

realize that they must willfully lay down emotions and pick up strategy, using their knowledge of the rules of engagement to skillfully maneuver through this game in which they find themselves. Again, it is the parents who are also teachers who quickly realize that teachers cannot possibly deliver what their child needs. One parent was particularly eloquent in her discussion of her acceptance, as a teacher, of the system's limitations.

I experienced it myself last year when I had this autistic girl in my class. My heart bled for that poor child but there wasn't anything very much that I could do for her... except be nice to her and make sure that I spoke to her every single day because I knew that none of the students did. She's in high school now and I often wonder about her...if anyone speaks with her now.

In these realizations parents decide that they must create the support that their child needs and strategically implement it. This strategic intervention includes the hiring of private counselors, assessors, tutors, and psychologists in their attempt to respond to their child's needs. In fact, a privatized system of care and support appears to be well entrenched in the experiences of the parents in this study. This strategy has a dual benefit of bringing individualized help to their child but also strengthening their "side" during these meetings and lessening their sense of aloneness.

My child had a psychiatrist, a private counsellor, a tutor and a private pediatrician but they are never invited. When they attend, I insist on it and I pay for it.

Collaboration is something that costs a fortune and is only an illusion then because the minute they walk out nothing comes of it. The services that he has had that have made a difference are the ones that I have fought for tooth and nail and they are

certainly not what the schools have identified or arranged. They are the ones that I have gone outside to purchase.

The age of expert knowledge being held by professionals is clearly past, according to the experiences of these parents. Few educational professionals understand OCD and fewer still are sensitive to the challenges of raising a child with it. Parents acknowledge the complexities of the condition and admit that they struggled to understand it at first. However, this realization becomes channeled into a determination to educate themselves through print material as well as the World Wide Web. Many of these parents are involved in local and national advocacy groups. They begin to see themselves as the true experts on their child and attempt to share this expertise with the staff by providing reading materials, videotapes and conference information. One parent reported hiring, at her own expense, two professionals to go to her child's school and conduct a half day full staff in-service. Other parents are less overt in their strategizing to educate the staff and share their new expertise. One gave an example so clever that it actually went unnoticed by the staff:

I have lent them books and have a manual on his file. I didn't know if it was being used so I took it back and highlighted the parts that were applicable to my son and then asked them to skim the book, paying particular attention to the parts that I had personalized.

While parents must be experts on OCD, they know the dangers of declaring expertise in educational programming. They "know their place" at the game table. Parents voice an

awareness of a need to exercise caution and report having to be careful with how far they push for support for fear of teacher reprisal, or *getting their backs up*. This fear is anchored in the realization that their child will have to remain with this teacher for the remainder of the year and that the parents will be continuing to look for support. *Staying on their good side* becomes central to the process, fueled in large part by an awareness that little by way of positive consequence will come from making complaints. Parents see teachers as not being held accountable for any lack of support and view the appeal process as ineffective. Higher authorities, such as the school board or Department of Education, tend to refer parents back to the school, despite the school being the source of the frustration. In fact, parents are fully aware that all professionals in the school system are members of the same union who feel that they must protect one another against accusations.

There's a fine line between knowing how far to push to get the help he needs so that he's afforded the opportunities and when to draw back. There's a point beyond which you get diminishing returns and when it becomes a battle of the wills. There is absolutely no accountability in that system...The system closes in really fast when someone screws up and the bigger the screw up the tighter and faster they close.

When you force things you really get their back up. If you go to the district office you totally get their back up. They completely fail to see that you had absolutely no choice but to go there because you have been so disempowered, and that you obviously feel that the only way to get any power is to go to a higher source. But it's a system that forces you there – not that it works, because all the district will do is refer you back

to the school and cover for them if they did something wrong. No one is ever held accountable no matter how blatantly they are wrong.

The understanding that a double game is being played and the realization of their limitations in influencing the system actually enable parents to focus on their strategy and vigilance. Accepting the limitations of the teacher in implementing support and seeing the system's inability to prioritize care, parents set aside emotions and become keen observers of the system. They attend meetings to learn what is happening. They use the rhetoric but do not buy into it. They walk through the process, but always work a subtext. By strategically re-working the flaws of the system and becoming increasingly skilled at playing this game, parents channel their disappointment, loss and frustration into a system of support for their child. By doing so, they rediscover their innate ability to nurture. They stumble upon a sense of power.

I struggle with telling them [teachers] off. Should I really blow it and tell them what I really think? I have these imaginary conversations when I walk in there and say, "I know that you have 34 in your class. I know exactly what you have on your plates and I know what a thankless job you seem to think you have. But by the constitution of this country my child is entitled to an education the same as the child sitting next to him who doesn't have this disability, so you are going to do all you can to help him and I'm going to be on your back every single day to make sure that you do".

The Outcome

What results from this constant process of balancing their frustration with vigilant, strategic intervention? How do they make sense of the realizations that the space that they

share with teachers has moved from being shared, to negotiated, to contested? In completing this final part of this chapter we explore this quiet acceptance of the futility of parents trying to change the system and discover the meaning and strength that has grown under the surface.

Parents believe that their initial impressions were accurate and that the ISSP model does not deliver on its intention. Initial promises of school staff and the wording of the policy established a false hope that the system would accommodate vulnerable children and give the support that they required. Early in the collaborative process parents discover that they have been misled by a policy, which they feel, rests on language more than sensitive pedagogy. The disappointment that this brings and the inability to move beyond token support result in a sense of hopelessness for parents. The system is viewed as being both unable to deliver on an ethic of caring and unwillingly to work towards change. Parents see their efforts of change as being in vain, feeling increasingly pessimistic that care can ever be dictated by policy.

I showed up at the Department of Education and refused to leave until I met with the woman in charge. I even got a meeting with the Minister of Education, who also rushed in late, apologizing as he entered the room. He sat and listened to what it was like to have a child with Obsessive Compulsive Disorder in the school system and heard all of our concerns. A few days later we got his form letter in the mail thanking us for our input and then referring us back to the board, who then referred us back to the school, who referred us back to his teacher - and nothing happened. What did it accomplish? What did any of it ever accomplish?

It is only by moving into a sense of disillusionment and futility of trying to change the system that parents discover their own power within themselves. This disillusionment with the system brings parents to a place of creating supports by themselves. The game is played so that they have access to the players, and awareness of the school program that allows them to be strategic in their intervention. Emotions are laid aside and energy is focused on “winning” for their child.

Some days I think I'll win. Some days I don't. You can't think that. You can't wonder if you'll win. You have to believe you will. You focus on his strengths and you fight. It is such a game. Crazy, ludicrous in fact, but you have to play it.

You don't make sense out of it, but you don't want to lose your child so you go on out of sheer desperation and you hide your disappointment. You have no choice, you can't even tell them that you are angry, that you are hurting, that you are terrified for your child.

Disillusionment extends beyond the ISSP process to include the educational system as a whole. The school is seen as being a *closed system*, where teachers *look out for themselves*. It is a system that is seen as being too big to change, too rigid to bend, and too large to care about an individual child. Parents view it as having a rigid *black or white* rule system with which all children must comply, regardless of need. This message is received loudly through practices such as frequent suspensions of the child (in grades as early as primary school) for displaying their compulsive behavior, and more subtly through ignoring children's struggles to cope. Parents view these suspensions as being

the school's preferred way of dealing with their child and it becomes a metaphor for the rigidity of the system. They interpret this as a clear message that their child has to fit into a system that will not adapt to accommodate him/her.

Suspensions become a powerful example of how much their initial relationships with the school have changed. The full acceptance that their child received before diagnosis is now juxtaposed against being told that she/he cannot attend because of his/her condition. An acceptance of "individual differences" is outlined in the policy but not reflected in their experiences. Parents view the primary goal of the ISSP team as supporting the child in the learning environment of the school community, yet the practice of suspensions continuously removes them from this environment.

One principal warned, "This is how we do things around here". When my son was assaulted by another student, he was given a three-day suspension, while my son was given ten detentions for starting the fight. I proved that he never started it and the principal said, "Okay, then eight detentions". A few months later another incident happened when a group of kids were taunting him in the morning and he walked away but of course they followed. Finally [son] turned and told them to F- off. He was given a three-day, out of school suspension and twenty-five paragraphs to write, actually copy, because the principal composed it and he had to copy it. It was like a confession. I was very concerned about the severity and challenged the principal on it, saying that it was much more severe than the student who assaulted him received. He said that I had challenged him on the ten detentions and he wasn't going to give in on this one, that I expected my child to be treated different. I said that yes, I did expect him to be treated different because he is different. He isn't like everyone else.

Parents interpret this as being a powerful message of “you don’t belong here”. The earlier the message comes the louder it is heard and the faster it brings disillusionment. The faster disillusionment comes the quicker parents are to become strategic in their efforts to help. The earlier they begin strategizing the more skill they acquire. This process of double-gaming further divides parents and teachers and deepens the fractures that are growing in this collaborative planning process. This also challenges some of the parents’ fundamental understanding of schooling. The practice of parenting, with its unconditional love and attunement to needs, is contrasted against the practice of teaching, with its focus on goal attainment in a structured, equitable environment. Parents have long given up hoping that they can change the system or that care will automatically appear one day. This letting go of the struggle, this acceptance of the model’s failure, this acknowledgement of their aloneness brings a sense of personal stability and strength. By being forced out of the space between parents and teachers, mothers’ discover their individual power. It might be a strange path towards empowerment but it is indeed effective in the help that it gives the child. One mother whose child was diagnosed while still in primary school demonstrated this. She related countless experiences of suspensions and frustrations so overwhelming that she actually changed schools three times in her son’s first four grades. Observing at the ISSP meeting for her child was radically different than the meeting discussed earlier in this chapter.

The meeting started 15 minutes late, due in part to the child’s pediatrician being delayed. The mother had arranged the meeting so that the doctor could be in attendance and insisted that the meeting not start until she arrived. The mother had also arranged for the child’s private counselor to attend the meeting. In addition, a family friend trained in

special education was in attendance, whom the mother introduced as the person who would be keeping the minutes. There was no discussion on this matter. The mother had brought a stack of blank paper and circulated them to anyone who needed to keep jot notes. The mother chaired the meeting and began by outlining the agenda. During the meeting there were fourteen announcements over the school's PA system, with each being repeated. When this occurred the mother stopped the meeting and resumed discussion afterwards. At three other points she again stopped the meeting saying that she did not understand and wanted clarification of the points discussed. One of those times concerned the forms which the counselor asked her to sign. She made it clear that she would not sign until she understood why. At the end of the meeting the mother informed the participants that she was heading to Manitoba the following week to attend a national conference on her child's condition and that she would be returning with information for them.

In explaining why she had become so involved in both her son's program and the parent group the mother's response speaks to the essence of the outcome of this process:

I don't miss a support meeting and I totally empathize with what I hear. I know I would be telling the same story if I had stayed in either of the previous schools. Since I started chairing the meetings my experiences have changed. In fact, other parents can't believe that I am actually the manager of his program. They ask how I got that role. My response is I took it. I hold the school accountable now. If they say they will do something I make sure they do. I call them at home if I have to. I still get sarcastic comments like they need a big table for meetings with me, but I ignore that. No one

will ever make me feel as bad as I did when he was in primary school. If I never had control I would still be crying my way through those meetings.

Summary

The entire process has been disempowering. I have felt guilty. I've felt humiliated. I've felt embarrassed. I've felt like walking in there with a bag over my head. I've felt desperate and completely at their mercy.

It is no coincidence that this mother used the past tense to describe this myriad of emotions. In traversing this space and hearing the experiences of these parents we discover that action does indeed come from thwarted hope. In exploring the space that exists between parents and teachers we discover that the ISSP process has a marked impact on that space, defining it as contested ground which breeds conflict and disillusionment. Surprisingly, this is the same ground that forces a resolve in parents to become supporters of their child. The metaphor of the game, initially used to describe the system's failure to either recognize or respond to their child's needs, becomes transformed into the metaphor that describes their strategizing to re-work this system so that it works for them.

Parents view this nexus between their experiences and the language of the policy as a prioritization of perception over care. They see the language-dominated policy as a mask that attempts to portray a caring and child-centered system that does not exist for them. The disillusionment that this brings places them in opposition to teachers, yet with a resolve to continue in their attempts to help their child. Such determination, against what seems to be incredible obstacles, speaks to the essence of parenting and

nurturing of these children. It is within this world of practice over policy, of child over children, of reality over intent that these vulnerable children exist. Ironically, a model that espouses role parity and equality creates clear divisions and conflicts in which the needs of these children get lost and forgotten.

The phenomenon of attending meetings reflects this personal cost and contradiction of intent. The ISSP model articulates a prioritization of parental involvement towards empowerment of the child via a shared decision-making model within a context of interagency planning. They see this as not happening. Despite a carefully worded approach, its practice stands in strong opposition to its language. Vigilant of the process and detached from the emotional cost, these mothers become skilled at working the subtext of the very process that frustrates them. In the calmness of accepting that the ISSP model will not work for them, they find their strength. Leadership and power comes to them by default.

Chapter Five: Reflections on the Journey

Introduction

I attempt to put closure to our journey by affording an opportunity for us to step back and reflect on a map of our travels and the snapshots that we have gathered. We will revisit the lessons that this journey has afforded on the three phases of this experience: the process, the coping and the outcomes, framing such within the context of the literature reviewed at the outset of our travel. We will re-examine the methodology that we used to explore this space and locate these themes. Finally, we end with a discussion on the implications of this study for teachers, parents, researchers, and policy makers. In doing so we, like the parents in their own process of telling, return to the beginning and reflect on our own process of entering into this lived-world.

My journey to transform experience into text began in chapter one with a self-examination of my own experiences, interests, beliefs and philosophy. This articulation served as a touchstone throughout this project, a way to monitor and delve deeper into how this study was both impacting on my beliefs and shaping the writing of it. My diverse experiences in the field of special education in Newfoundland and Labrador left me questioning the experiences of parents in the collaborative planning process. I had assumed that my “insiders view” would afford me the opportunity to identify a breakdown between policy and practice. What I was not prepared for was the extent of this breakdown and the depth of parents’ insight into the ISSP process.

This bracketing process also prepared me to remain focused during the often painful task of hearing these stories and of reflecting on my role developing the ISSP and in its implementation. Moustakas (1994) had described this process which I was undertaking as a “heuristic journey” that would prove “disturbing and even jarring”

(p.13) and indeed it was. Van Manen (1997) commented on this challenge, seeing it as the aim of phenomenological research to,

...transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience (p.36).

My own emotional reactions would act as the ballast for my journey as well as the compass to guide my inquiry. In reflection, I discover that I am both animated in the text of these parents' experiences as well as transformed by its articulation.

The second chapter set the academics of the phenomenon that I would be exploring. A paradigm of inclusion based in a philosophy of civil liberties was explored, and differentiated from special education. The shift towards a model of case management that reflects collaborative, interagency planning served as the rationalization for Newfoundland's ISSP model. Finally, the literature on parent involvement that included participation, empowerment and power structures in the planning process was examined. This process was extensive, and in fact resulted in three articles being published. Being grounded in literature enabled me to deepen my search for the underlying thematic meaning structures that lay buried. It now affords us a starting point in explaining why this model has failed these parents and how they derive hope from this realization.

Chapter Three discussed the phenomenological method which, in hindsight, was a wise choice, as phenomenology matched not only my interests and background but also the research question. I purposely selected the hermeneutic approach outlined by van

Manen in my aim to understand how parents attempt to derive meaning from their experiences. In addition, the writings of other phenomenologists, such as Moustakas (1994) and Husserl (1970), as well as other researchers such as LeCompte and Preissle (1993), Guba and Lincoln (1998) and Berg (2001), helped solidify a strong methodological foundation to the study. Later in this chapter we explore the methodology in greater detail.

Chapter Four served as an attempt “to involve the voice in an original singing of the world” (van Manen, 1997. p.13). To this end, I attempted to write with a language that is reflective of the voice of parents and accessible to the reader. Where possible, I included the parents’ quotes to honour their telling and amplify the message. My goal was not to retell their story but to organize the message in such a way as to illustrate the structures and essence of this shared experience. The themes that emerged stay embedded in the story, serving as subtle reminders that to appreciate the theme is to contextualize the telling. Finding ourselves standing beside these mothers on this playing field that they so powerfully described, we are able to appreciate both the challenge to remain engaged as well as the skill that comes from being forced to play the game.

Reflections on Methodology

In this section we will revisit and re-examine the appropriateness of the phenomenological method in exploring this research question. This discussion will touch on the issues of validity, thematic extraction and writing.

Given that my research question addressed parents’ experiences and how they interpret shared phenomena, the selection of a method of inquiry was relatively straightforward. I was, in fact, asking a phenomenological question that sought to identify

meaning from a shared-experience with which I, as researcher, was very familiar. Meyen & Skrtic (1995) stated, “Ultimately, I am concerned with the nature and implications of special education practices and discourse” (p.660). This statement encapsulates my research interest and it was in this light that I attempted to illuminate the perspective of parents in this practice.

My decision to be interviewed about my own experiences with case planning proved extremely helpful. Not only did it give me an appreciation of the process of being interviewed but it also forced me to explore more deeply the extent of my assumptions and opinions of which I may not have been fully aware. In effect, I released control of my own self-exploration and opened myself to a thorough examination, a catharsis of experiences, thoughts, and assumptions. In so doing, I identified common ground between the participants and myself, thereby freeing myself to accompany parents to places not travelled and to perspectives not seen. My experiences, which I initially believed to be quite extensive, become shadowed by the breadth and depth of the parents’ experiences. While this lends to the validity of the study it also facilitated the writing process.

This process of exploring my previous experiences with this phenomenon allowed me to foresee the terrain that I would travel. However, little had prepared me for the climate that I would encounter or the challenge to articulate it. As a student, I had readied myself with a rigorous literature review and an in-depth examination of methodology and procedure. As a counsellor, I was watchful of non-verbal language and affect, both in the speaker and in myself as listener. As a teacher, I was familiar with both the policy and the process that they described. As a researcher, I knew that the language they used, the

words both chosen and absent, would become central to my articulation of the phenomenon. However, weaving this into a textual reflection would become a challenge marked by emotion and frustration.

The effectiveness of phenomenology does not rest on the researcher entering into the shared experience of the subjects but rather challenges the researcher to remain oriented so as to examine the experience and articulate its essence. While phenomenology felt like a natural match for me, writing proved to be a task that often overwhelmed. It was a process that took months of reflection and resulted in countless rewrites of the text. Journeying into the lived-world of these parents necessitated an ability to experience it fully and also separate from it so as to understand and describe it accurately. This duality of approach was discussed by van Manen (1997),

On the one hand it means that phenomenological research requires of the researcher that he or she stands in the fullness of life, in the midst of the world of living relations and shared situations. On the other hand it means that the researcher actively explores the category of lived experience in all its modalities and aspects (p.32).

In many ways, this rigorous rewriting cleansed my own disillusionment and anger that such practice could occur in my profession. Not only was it challenging to hear the meaning structures emerge from these parents' stories but also to process the implications of such for my profession. I found myself torn between hearing and desponding to these parents and defending my practice and colleagues. The constant revisiting of the text,

reflection on the language and reworking of the document afforded a multiple perspective examination of what I was hearing, as well as how it affected me.

One powerful example of this occurred during an interview with one mother who was also a teacher. She was relaying how her child's principal became annoyed with her during a lengthy discussion on why her son should not get suspended. In referring to her son the principal told her, "*You know, he's hard to take*". This comment haunted me for many months, not only for how it must have affected the mother, but how it was affecting me. How could I begin to explain why a colleague of mine could make such a comment, in the context of a planning model that I supported, in a province where I am seen as a leader? Having the bracketing experience allowed me to frame this within the context of my experience, honour the emotions that surfaced, and then separate myself from it so as to focus on how the mother derived meaning from it. In many ways, the writing process reflected a constant removal of my own emotions and disappointment so that the core could be displayed; a constant chipping away at the stone so that the sculpture could emerge.

My choice to select subjects from one group of exceptionality proved wise. Inclusive education is a broad area, serving children of diverse needs. Selecting only parents of children diagnosed as having OCD narrowed the experiences significantly. Even within this homogenous group there was diversity, with some children being diagnosed with Tourettes Disorder as well as OCD, and other children being diagnosed as having significant anxiety disorder with OCD symptoms. Children with OCD usually present with challenging and perplexing needs that can, in many ways, be seen as an extreme for the ISSP system. My goal was not to select one of the most challenging

groups of children through which to examine the ISSP process, but rather to find a window into this phenomenon with a similar group of vulnerable children. Ironically, these parents were so focused on the process of planning that they proved to be an ideal group to study. They had learned to look beyond their child's particular and changing obsessions to the process of supporting that child. It permitted us to be ever-focused on the ISSP model and not become mired in individualized manifestation of need or condition. Understanding the experiences of these parents assisted us in beginning to understand the nature of interagency planning. In doing so, we fully acknowledge that other viewpoints are available and may well be of equal significance. A comprehensive understanding of the space that exists between parenting and teaching might well be facilitated from several of these perspectives.

The flexibility that is core to phenomenological method not only accommodated this diversity but also allowed me room to respect the individual needs of the parents. While I had initially planned for observations of ISSP meetings and subsequent individual interviews, not all the parents wanted to do this and not all could schedule it. Van Manen (1997) had cautioned that in gathering the lived-experience of subjects, methodology should allow for "a certain openness...for choosing directions and exploring techniques, procedures and sources that are not always foreseeable at the outset of a research project" (p.261). My initial thoughts were that attending a meeting would grant a shared experience from which to begin a conversation. These parents did not need their conversations facilitated but rather a platform from which to speak. Eager to tell their stories and equally eager to have them heard, these were parents who wanted recognition of their struggles to get help in a system designed to deliver it.

Attending three ISSP meetings as an observer, after having attended countless meetings as a participant, allowed me a different perspective on what these parents were telling me about the inefficiencies of the meeting process. It afforded me the opportunity to “see” what these parents were describing and to distinguish it from similar previous experiences. It also afforded an opportunity to add to the reliability of the findings in that what I witnessed in the meetings was what the parents were disclosing in the interviews.

I was becoming increasingly intrigued by the commonality that was emerging in these stories. A focus group offered a valuable opportunity to explore this further. The value of this group was especially evident in the articulation of the disillusionment at the core of their experience and the detachment from their emotions that is required for parents to keep functioning. Parents acknowledged publicly, perhaps for the first time, that they play this double gaming at a personal price in an attempt to help their child.

The rigorous phenomenological method, with its recursive, circular process of identifying themes gave rise to common phrases, identical metaphors, similar concepts and shared frustrations that expedited the process of locating themes. While other methodologies may have been helpful in examining aspects of the collaborative planning process, none could have been flexible enough to respond to the experiences of parents. Other methodologies might not have pushed for a deeper understanding of the essence of this experience, wherein we uncovered a strength that begins in their dogged acceptance of the model’s limitations.

Reflections on the Themes

We now turn to revisit the products of the method and discuss the themes within a context of the literature reviewed earlier. While the themes remain embedded in the description of the phenomenon, here we can lay them out more distinctly.

These themes emerged within three frames:

The process:

- Having a child with OCD radically alters the interaction of parent and teacher
- The ISSP meetings distinguishes parents and teachers as opponents in a game
- Parents are disillusioned with a breakdown between policy and practice
- Adoption of a “game” metaphor makes it possible for parents to stay engaged
- The model sets teacher up for failure

The coping:

- Vigilance to the child’s development and the schools accommodation occurs
- A double game occurs where parents re-work the system to create support for their child
- Detachment from their emotions enables parents to play the game
- Privatization of support is often necessary
- Parents feel a sense of aloneness in supporting their child
- Parents develop expertise on OCD
- Parents perceive teachers as not being accountable for their practice

The outcome

- Parents find “power within” during their strategic game playing
- Parents become determined to support their child

The Process

In examining the process for these parents we unearth much of what has been previously identified in the literature that was explored in Chapter Two: the breakdown between written and enacted policy (Able-Boone, 1980; Armstrong & Barton, 2000; Fulcher, 1989; McDonald, 1981); the many inequities and power differentials in the planning process (Goldstein, et al, 1980; Quiroz, 1999; Rock, 2000; Turnbull & Turnbull, 1986; Vaughn et al, 1988); the limited understanding of a true philosophy of inclusion (Gale, 2000; O'Brien & O'Brien, 1996; Slee, 2001); the absence of an ethic of caring (Noddings, 1992; Sergiovanni, 1994); and the overuse of language (Danforth, 1999; Fulcher, 1989).

What this study does, however, is pull us beyond this breakdown, into the world of how parents cope with such realities and onwards into the even more nebulous space of the consequence of their being forced to function in this world. While other research has discussed generalizations, we discuss the particular realities of this lived reality.

While interagency case planning has been viewed as a model towards greater empowerment of the client (Raif & Shore, 1993), these findings identify that little is changed by interagency approaches. In fact, our findings support earlier work which points out that in promoting change for the students we can't ignore parents' and teachers' sensitivity to the family's needs (Perlmutter & Trist, 1986; Welch, 1973). It underscores a need for a greater paradigm of care, not only for vulnerable children, but also for their desperate parents and frustrated teachers.

The study powerfully illustrates the difference between special education and inclusive education. While Newfoundland and Labrador use the language of inclusion, it

follows the practice of special education. The experiences of these parents are really located within a model of special education that uses diagnostic and prescriptive approaches of categorizing children by focusing on their deficits. Meetings tend to focus on what is wrong with the child and how she/he does not fit the system, rather than how to change the system to accommodate the child. While ISSP meetings promise an appreciation of diversity, manifestation of this diversity will result in few accommodations, and even suspension. We are left to wonder what the experiences of parents would be in a system that embraces its “ethic of caring” (Noddings, 1992) and works to create a school community that values diversity and recognizes the inherent worth of individuals (Gale, 2000, Sergiovanni, 1994; Slee, 2001).

The Coping

A game playing metaphor brings us to a deeper understanding of the process of coping by laying bare the actual game strategies. The ISSP meetings afford parents the opportunity to watch and learn about the system’s limitations and weaknesses, as well as present opportunities for them to compensate for the system’s inefficiencies. In this transparency a vulnerable teacher emerges. Their struggles are visible, as are their attempts at coping with challenging children. Despite the parents’ perception of a lack of accountability for teacher practice, we begin to suspect an absence of understanding, an erosion of care, and a loss of commitment. Parents see that teachers are being put on the line and their failures are becoming more apparent. They see teachers as realizing this, and, with this awareness, pulling back as a means of self-protection.

We are, in fact, left in awe of the determination and skill that these parents deploy in their vigilant attempt to make this system work for them and to create the help that is

needed. Parents use the model of interagency planning for their own purposes, hiring a multi-disciplinary support team, using the meeting structure and creating a shared plan. While they remain covert in this re-working of the system, they create what the model initially promised. It is not the model that they see as failing but the system's implementation of it. They see teachers as being untrained, unaware and unaccountable. What emerges is a clear call for increased pre-and post-service training for teachers in collaboration, as well as a review of accountability procedures.

In examining this process we discover that the model of citizen participation proposed by Arnstein (1969) holds a parallel for these parents. As discussed in Chapter Two, Arnstein used tokenism to reference limited participation; the same phrase used by these parents to describe their participation. If we espouse a model that promotes true equality of parents in the collaborative decision-making approach, Arnstein's metaphoric ladder, in particular the final stages of "partnership", "delegated power", and "citizen control", defines our goal. How then, do we ensure that parents find power through the model of management and not despite it? How can we create true partnership, delegate real power and ultimately enhance citizen control?

The Outcome

The victors of this game are not the system, the parents or the teachers but rather the children who benefit from their mothers commitment to participate in this double-game. In accepting the inadequacies of the system, parents resolve to compensate and by becoming skillful in playing the game, parents stumble into their power. This outcome supports previous research that an internal locus of control (Dempsey & Foreman, 1997), valued participation in care provision (Pedlar et al., 1999) and sharing information and

knowledge (Dunst, 1997) facilitate power for the individual. What this study does, however, is outline the ability of parents to empower themselves despite a system that fights against it. As one mother powerfully illustrated, power and leadership can be taken back. Despite standing on contested ground in a system that oppresses, these mothers display skill and determination to be victorious and by doing so display a sense of personal power that the model failed to provide.

In looking back to the literature we begin to understand the outcome of this process more clearly. The experiences of these parents support the studies done on power structures within hierarchical systems (Bishop, 1994; MacDonald, 1999; O'Brien & O'Brien, 1993; Wartenberg, 1990). What this study does is take us beyond the identification of these power-over dimensions, and the failures of power-with, into the recognition, and indeed utilization of power-within. The ISSP process teaches these parents that they have a marginalized role within a system that they perceive as being oppressive. A need to protect and nurture compels them to understand the system, become experts on OCD and then strategically use it in their process of finding their power. In doing so, they stumble into a sense of *power to* (Wartenberg, 1990) affect change for their child.

Implications

In this final section we switch our focus from reflection to introspection, from looking back at our travel to looking ahead at the journey before us. We explore how this new awareness, this acquired insight, these lessons will transform the practice of collaborative planning for children with OCD. Van Manen (1997), in discussing the implications of phenomenological research, articulates that the goal is never to generalize

the findings in an attempt to improve practice or develop theory, but rather to understand an aspect of our world. This study “does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world” (p.9). In this light, the findings of this study become, what van Manen refers to as a “theory of the unique” in that teacher practice and pedagogical orientation to working with children and families can be strengthened. Although the study was not intended to be generalized, it does invite us to look into the experiences of parents in this collaborative planning.

As parents, this invitation to action is voiced as a challenge to become more active in the process of creating support for their child. The parents in this study found a quiet acceptance in the sad realizations that the model was not going to deliver what it promised and their efforts to change the system were in vain. In this realization they began the process of strategizing and acquiring insights and skills that created the support their child needed. Power came to these parents because they would settle for nothing less. As parents, this touches on the essence of nurturing and unconditional love. As care providers, it speaks to the determination to help vulnerable children. In seeing that this is indeed possible and in now having a map provided, the journey becomes possible for other parents. Having these themes laid out into three distinct phases affords parents the opportunity to view their own experiences and discover what they may not have seen before. In doing this, an invitation surfaces to help other parents, via approaches such as mentoring, as well as to begin the process of helping teachers find their way through this contested space.

As a university professor, I hear an invitation as well. The results of this study identify a clear need for greater teacher training on collaborative planning and enhanced sensitivity to the needs of families. Equally, it calls for co-training with other service providers such as medical practitioners and social workers to ensure collegial model of planning that facilitates true collaboration. Maich (2002), in a recent study of Newfoundland teachers' familiarity with collaboration, identified that neither special education nor regular classroom teachers felt that they had the training or resources to implement true collaboration in their practice. The experiences of these parents illustrate these results and challenge us to action. A beginning step might well be to take Danforth's (1999) advice in naming power as an obstacle and to promote self-analysis of educators into how they exert power to the detriment of their profession. This study illustrates that empowerment is not an outcome of any model but must be facilitated, taught and nurtured. In doing this, a thorough understanding of power-over, power-with and power-to is essential.

As researchers, this invitation holds many possibilities. One immediate question concerns the perspective of teachers on their involvement with the ISSP process. Other phenomenological questions include the experience of fathers in parenting these children. Why are they so noticeably absent from the process? How do these mothers derive meaning from this absence of support from their child's father? The study also raises interesting research questions into the accountability process of teachers and the effects of teacher unions in this process. What is the experience of teachers in dealing with incompetence and lack of accountability among their peers? Yet another area for future study would be a participatory action research project on empowerment of parents in the

collaborative decision-making process. It is this last area of research that holds particular interest for me. Having heard such experience, I cannot remain still.

As educators, this invitation raises some interesting questions for teachers and policy makers as they enter into collaborative decision-making. Certainly sensitivity to what van Manen references as pedagogic thoughtfulness and pedagogic tact is called for in working with these families. Given the demands placed on teachers, the diversity of their classrooms and the diagnostic prescriptive nature of their jobs, such a response is not easy. Van Manen (1984) identifies this challenge for teachers, who he feels have to focus on future outcomes at the risk of a loss of focus from the immediate. He challenges teachers to have a more holistic view of a child's development and to cease closing themselves "off from the possibilities that lie outside the direct or indirect field of vision of the expectations" (p.65). He articulates that such a limited perspective is an innate irony of the teaching profession and a contradiction of the practice. He writes, "the language by way of which teachers are encouraged to interpret themselves and reflect on their living with children is thoroughly imbued with hope, and yet it is almost exclusively a language of doing – it lacks being" (p.65). He raises a challenge for educators to "...act responsibly and responsively in all our relations with children, with youth, or with those to whom we stand in pedagogical relationships" (p.12)

Teachers should be comforted by the eagerness with which these parents welcomed me into their lived-world. These are parents who want to be understood. They are not mired in frustration or anger. They can't afford to be, but instead are moved to action in a vigilant process to help their child. By accepting this invitation we are afforded greater insights into the ISSP process and by so doing can mutually move

towards improved practice. This expertise that these parents have acquired, this ingenuity of problem solving, this resolve to stay focused on solutions can guide us as educators towards effective supports for children through the process of true collaboration and, in doing so, can help create true inclusion.

These parents challenge teachers and policy makers to recognize the ineffectiveness of using special education practices to promote a philosophy of inclusion. It illustrates the outcome when professionals stand in a diagnostic and prescriptive model and use the language of diversity appreciation and accommodation for students. It illustrates that role-parity cannot occur when professionalized approaches dominant practice. These mothers challenge teachers to “walk the talk” of inclusion and cease resting on the transparent political use of language. The challenge to educators is to have their practice reflect philosophy.

As policy makers, these themes become more than an invitation to action but a challenge to respond. How do we prioritize enacted policy over written policy and promote what Danforth (1999) references as a dialogue of democracy? Is there a role for mediation training and alternative dispute resolution? Parents were supportive of the philosophy that the language of the ISSP model reflects. They realized quickly that this philosophy will never be realized with such a special education approach. The ISSP process in Newfoundland is indeed a reflection of emergent trends but it is an equal reflection of the breakdown between policy and practice (Fulcher, 1989; Loxley & Thomas, 1997; Ware, 2000). If Smith et al. (1998) are correct in predicting that the next stage in special education is empowerment, policy makers need to acknowledge this

nexus. They must develop enacted policy that is effective for true collaboration by challenging implementation to reflect intent.

The findings of this study call for an open dialogue to facilitate, "...a discourse that acknowledges the cruelties and hierarchies of the past and present while intentionally pressing forward toward an equality of voices, an even plane of speaking and writing, [with a goal of creating a] democratic community" (Danforth, 1999, p.746). In democratizing schools to create communities of inclusion, Danforth articulates a 4-step process:

- Switch from a focus on "equal opportunities" to one of social justice that provides opportunities for enhancing dignity and empowerment.
- Demystify the power of professionals in decision-making processes.
- Focus on the nitty-gritty details of what actually works.
- Acknowledge that it is not an easy or a simple process (p.748).

In accepting this invitation, in beginning this dialogue, and in looking ahead for ways to improve our relationships, these parents offer us powerful teachings. It becomes a personal choice whether we open ourselves to hear them. Van Manen (1987) discusses this invitation to action that emerges from phenomenological research. He writes:

And so to become more thoughtfully or attentively aware of aspects of human life which hitherto were merely glossed over or taken-for-granted will more likely bring us to the edge of speaking up, speaking out, or decisively acting in social situations that ask for such action....the thoughtfulness phenomenology sponsors is more likely to lead to an indignation, concern, or commitment that, if appropriate, may prompt us to turn to such political agenda (p.154).

In having completed this journey and exploring this terrain of interagency case planning from the perspective of parents, inertia seems impossible. I am reminded of advice that I received early in my teaching career, that “when you stand in front of your students you cannot help but teach”. This advice now seems applicable in that having heard these stories, having discovered these truths, we cannot help but respond. Our journey back will forever shadow our journey ahead.

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Appendix A: Glossary

Collaborative decision-making: Collaboration is defined as, "...a creative partnership that can be used by teachers, parents and administrators to achieve..." (Tiegerman-Farber & Radziewicz, 1998, P.66) mutually identified objectives to meet the needs of special education students.

Parents: For the purposes of this study, parents included birth, adoptive, single parent, foster parents or any professional/para-professional who acts in a guardian capacity. Where appropriate both parents were encouraged to attend. Parents should have had at least two years experience in the individualized planning process.

ISSP (Individualized Support Services Plan): Often referred to in the literature as the Individualized Education Plan (IEP) (Winzer, 1999; Heward, 2000), this references both the process of meeting and developing a plan as well as the written document that outlines the strategies and interventions developed.

Inclusion: Inclusion is defined as "the belief or philosophy that students with disabilities should be integrated into regular education classrooms, regardless of whether they can meet traditional curricular standards (O'Brien, Snow, Forest, & Hasbury, 1989, cited in Friend, Bursuck, & Hutchinson 1989. p.6).

Special Education students: Students diagnosed with Obsessive Compulsive Disorder were identified by their participation in the ISSP process. Signed parental consent was required at all stages of this process.

Appendix B: Bracketed Experience of the Researcher

My experience with this collaborative planning and decision-making process is very broad, as is my interest in inclusive services for citizens with exceptionalities. In an eighteen-year career in education I consider myself very fortunate to say that I have taught at all levels of our educational system, from preschool to university. Central to this spectrum has been my involvement with special education through positions that ranged from specialist teacher, district coordinator to university professor. These positions followed a short, though intense, career in the residential support system where I worked as group home counselor and live-in coordinator with young adults with cognitive impairments. Although I was a young student myself at the time, finishing an undergraduate degree in special education, my introduction to the challenges and rewards of living with individuals with disabilities, certainly in a “parental” role, was impacting. My job was to live in the home with the young men and foster an atmosphere conducive to acquisition of independent living skills.

The model was reflective of the predominant social movement of normalization and integration fostered, in large part, by Wolfensberger (1972). The eighteen months that I spent in that position afforded me insights into the challenges and rewards of “family life” that instilled an appreciation for the perspective of parents that I have not forgotten. While my position was a “professional” one, I could not divorce myself from the emotional bond that was quickly formed with the “residents” and the pride and frustrations that resulted in their progress. Attending my first program planning team meetings for my “residents” and speaking from the perspective of their home, framing options within a context of home functioning, and lobbying for effective programs to

promote greater independence was among my most valuable training in special education. It was to be my first introduction to the varying levels of support and approaches used in the school system as well as the bureaucracy of special education planning. I remember well the feelings of frustration when teachers would not listen to what I was saying and when they attempted to minimize my perspective as group home parent. I recall the courage it took for me to voice my opinions, knowing that I was not “a professional” and that my input might well be challenged. It was also my introduction to the nexus between the theory of collaboration that I was studying as a university student and the reality of practice that I was experiencing in the field. I would attend university classes, learning the theoretical background to collaborative planning and individualized program development, while “living” the reality of daily life with disabilities and educational planning. School meetings became the litmus test of how well this literature matched reality.

In subsequent years, as I began my career as a special education teacher in primary and elementary schools, I intuitively had a respect for the challenges that parents faced and the valuable perspective that they bring to the planning tables. I would also hold to my commitment towards inclusion, continuing my involvement by serving on community based group home boards and community living associations. I was most proud when, at 26 years of age, I was chairperson of the residential support board which moved the final resident out of the province’s last institutional care facility for children with disabilities into a community-based group home. It was the culmination of a long struggle to change community understanding of citizens with disabilities and foster a paradigm of inclusion. My experience on these boards, certainly in a leadership position

at relatively young ages, afforded me invaluable insight into policy development, collaboration, conflict resolution and interagency planning. The lessons that these experiences taught me, the skills and perspective that I acquired, would become the foundation upon which my career in special education would be constructed. Collaboration and inclusion were at the heart of this perspective and would remain there.

My first teaching position was entitled: “TMR Teacher” (Trainable Mentally Retarded). It was obvious that I was entering a school system that was a step behind the community in both inclusive language and practice. Nonetheless, I prioritized strong communication with parents and welcomed their input into goal planning and program development. I joined two other colleagues as part of a new team hired to establish a program for “multiply disabled students” in a neighborhood primary/elementary school. Prior to our joining the staff these students attended school for varying amounts of time, where well- intentioned though untrained teachers took yearly “turns” in teaching them. I remember accessing the school’s main special education file that first September, a tattered manila folder titled “Needy Students” which contained everyone from “the handicapped kids” to the “orphans and poor”. A philosophy of charity dominated the approach used by the school.

Although today’s clinical language and legislated policy provisions were absent from that rural community, a new philosophy of inclusion was being embraced. Within one year, each of the students attended regular class with their age peers and were involved in all school activities and projects. When there was a field trip we loaded the wheelchairs into our cars and carried the students wherever the class was headed. Classmates, teachers and parents naturally helped and an unnamed philosophy of

diversity and collaboration began to grow. In fact, shared responsibility, role parity and collaboration defined our practice and would go on to become the anchor of my professional practice. Our new approach received a powerful endorsement from the most unlikely of places – the church. At that time, and for some time thereafter, the school system in Newfoundland was segregated according to religious denomination. School visits from the church hierarchy were common. I was surprised to hear the visiting bishop mention in a Sunday sermon that he was “most impressed” by how the school was “treating the handicapped children”. It brought validation, support and group ownership for the approaches that we were using, radical as they might have been. As a young teacher I was proud of this and was enthused by the community praise that quickly followed the bishop’s words. It would not be until fourteen years later, when I was in a district management position, that I would fully appreciate the innate sense of community that we practiced in those early days.

In the early 1990’s I was department head of special education at the province’s largest high school, developing and delivering programs for a wide variety of exceptional students. By then the special education policy in Newfoundland and Labrador followed accepted practice across North America and anchored parental participation in the planning process in policy and regulations (Department of Education, 1999; Government of Newfoundland and Labrador, 1996). This policy necessitated that each child have an Individualized Education Plan (IEP) that outlined the child’s strengths and needs and the required interventions. While the majority of the students enrolled in our program had a learning problem, many had co-existing behavioral/emotional issues that required intervention. Many were receiving support from social workers, counselors, psychiatrists

and/or probation workers. Our intention was to include all of these support services into our planning as well as foster strong communication with each agency. However, although each agency had case plans on the student, they also had protocols that prevented information sharing. As a result we acted in isolation from one another, unable to access treatment plans or resources, resulting in a fragmentation of intervention. The students and their parents would be our sole source of knowledge as to the goals and intention of the other practitioners. The resulting frustration was common, not just from the perspective of the educational system but also from each of the youth servicing agencies.

These teaching years would also introduce me to the ethics, competency and diversity of approaches in my profession. As a special education teacher I collaborated with most, if not all, of the school staff in planning for my students through a team teaching approach. The variation in levels of acceptance was sometimes amazing. Without question, most teachers were open to trying to accommodate my “special ed” students and were sensitive and supportive of their needs. In fact, I learned a great deal from these seasoned teachers through their willingness to share proven practices and techniques. However, others were most resistant. Some blatantly refused to attend meetings to discuss the needs of the students and others refused to implement accommodations. While the school administration could “encourage” the teacher to take the student, forcing them to attend meetings was counter-productive, as they would often bring a negative tone to the process. This same diversity of teacher approach and willingness to help was also common among my fellow special education teachers.

In 1996, following an interagency review by several governmental departments, the province recommended an interagency case planning approach that would result in collaborative planning and a sharing of resources. This new process would replace the traditional IEP with an interagency approach to case management, where all agencies involved would develop one common plan of intervention along with the parent and child (Government of Newfoundland and Labrador, 1996). The written plan titled an *Individual Support Services Plan (ISSP)* was finally implemented in 1996. (See Philpott & Nesbit, 2002 for an overview of the current Newfoundland model)

After completing a Master's degree in Educational Psychology (school counselling) I became aware that dynamics of these meetings included persuasion and influence, as well as the use of power-laced language to get desired outcomes and interventions. I witnessed a wide diversity of emotions displayed by parents, ranging from joy at successes to anger and frustration at school staff. I saw dynamics change dramatically when school board officials joined the meeting, or when the parents brought a support person. I watched meetings that flowed with clear communication and shared respect. I watched meetings that stumbled through a maze of rhetoric and one-way reporting on the child's progress. What I did not see was a consistent approach and a common understanding across all of these meetings for either the process of planning or its underlying principles, despite a strongly worded policy that mandated collaboration.

This interagency model was well entrenched in policy and practice by the late 1990's. At that point my career had grown to include a private practice as counselor and consultant in special education, which brought me to these meetings in the role of advocate. In many ways this new role was reminiscent of my earlier experiences with the

group home boards. After immersion in the school system, it felt as if I had indeed come full circle. Nonetheless, in this “new” role I would be asked to attend school meetings after having completed an assessment on the child and/or been involved in counseling intervention. More often than not, it quickly became obvious that I was seen as being aligned with the parent. In one case an angry school counselor who could not defend his lack of consistent support to the student called me “the hired gun”. Again, role parity and a spirit of open communication was a rarity in these meetings.

In September of 2000 I accepted the position of assistant professor of special education at Memorial University of Newfoundland. I am now involved in pre- and post-service teacher training. In this position I am responsible for teaching both theory and practice to the province’s teachers, many of whom complete the special education degree on a part-time basis while holding teaching positions. A consistent observation from my students on the theory of interagency planning and collaboration is that there is a significant nexus with local practice. I often hear, “that’s not the way it happens” or “in the *real world* it never operates that way”. I cannot help but remember saying the same thing years ago, as I worked in the group home and completed some of the same courses.

Appendix C: Letter of Introduction

David F. Philpott
 Doctoral Candidate
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October 1, 2001

Dear Parent/Guardian

I am a Doctoral student in the Community Rehabilitation & Disability Studies Program of the Faculty of Education at the University of Calgary. I am presently conducting a research project under the supervision of Dr. Nancy Marlett as part of the requirements for the degree of Doctor of Education. I am writing to provide information regarding my research project **A phenomenological study of parents' experiences in interagency planning meetings for their child in special education** so as to help you decide whether you wish to participate.

I am exploring the question "What is the experience of parents in the collaborative decision making process used in interagency planning models for students with disabilities, such as the Individual Student Support Plan". The goal is to understand the perceptions of parents during this process so as to increase awareness among professional participants. I believe that the benefits of obtaining this information include a greater understanding and increase support for parents who have children involved in special education. It will also strengthen teacher-training programs and contribute to policy/program development in the area of management systems for special education. Finally, greater awareness of parent's perceptions will promote increased sensitivity among professionals involved in these meetings. Given that special education is an extremely broad area I have purposively chosen to focus on parents of children with Obsessive Compulsive Disorder for two reasons. First and foremost, this is an area that has been seldom studied, resulting in little awareness of it in the educational field. Secondly, intervention for OCD requires a strong interdisciplinary team focus where collaboration is essential. I believe that identifying the experience of these parents will be interesting for all participants in the individualized planning process used in special education. Participation in this study will involve no greater risks than are typically experienced in daily life.

Should you choose to participate in the study I will meet with you three times. The first will be an observation at an ISSP meeting at the school. The second session will be an individual interview during which I will ask you to recount what happened during the meeting, from your perspective. The third meeting will be a more in-depth interview in which I will ask for your experiences and perceptions of these meetings, including

discussion on important themes that emerged from the observation and the first interview. The second and third sessions will be audiotaped (for ease of transcribing) and all collected information will be considered confidential.

You have the right to refuse to answer any question, stop the interview at any point and withdraw your consent to participate should you become uncomfortable. Given the sensitive nature of your child's needs, as well as your experiences in helping your child, every effort will be made to proceed at a pace that you are comfortable with.

Information will be collected in a way so as to insure anonymity. Each audiotape and transcribed notes will be coded with numbers and stored in a locked cabinet in a locked room. The coding information will be kept in a separate cabinet and all information will be destroyed two years after publication of the final report. While quotes from the sessions may be included in the final document no identifying information on you or your child will be included. Should the findings of the study be published, either in print or presentation format, no identifying information will be used and safeguards for anonymity will be rigidly adhered to. The final report will be available to you, free of charge, upon request.

In the event that you agree to participate the Principal of your child's school will be approached for permission for me to observe during an ISSP meeting. While the project will not directly involve the school, their permission is required so as to complete the observation. The nature of the project will be explained to him/her and a copy of your consent form will be presented. Additionally, permission for the project has been received from the Director of your child's school board (enclosed).

If you have any concerns or questions please feel free to contact me at 737-3506, my supervisor, Dr. Nancy Marlett, 403-220-5657, or Mrs. Patricia Evans at the Research Services Office at 403-220-3782.

Two copies of the consent form are provided. If you wish to participate please sign both, keep one for your records and return the other in the stamped envelop provided - as soon as possible.

Thank you for your co-operation.

Sincerely,

David F. Philpott

Enc/: Consent for Research participation form
Approval from Avalon East School Board

Appendix D: Consent for Research Participation

Consent for Research Participation

Research Project Title: “A phenomenological study of parents’ experiences in interagency planning meetings for their child in special education”

Investigator: David Philpott

This consent form, a copy of which has been given to you, 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 and to understand any accompanying information.

This project is exploring the question “What is the experience of parents in the collaborative decision making process used in interagency planning models for students with disabilities, such as the Individual Student Support Plan?” The goal is to understand the perceptions of parents during this process so as to increase awareness among professional participants. This information will lend understanding for parents who have children involved in special education. Given that special education is an extremely broad area the project will focus on parents of children with Obsessive Compulsive Disorder for two reasons. First and foremost, this is an area that has been seldom studied, resulting in little awareness of it in the educational field. Secondly, intervention for this population of students requires a strong interdisciplinary team focus where collaboration is essential. Identifying the experience of these parents will be interesting for all participants in the individualized planning process used in special education.

The study will be conducted in three phases. The first will be an observation of an ISSP meeting at the school. The second session will be an individual interview with the parent during which they will be asked to recount what happened during the meeting, from their perspective. The third session will be a more in-depth interview with the parent exploring their experiences and perceptions of these meetings, including discussion on important themes that emerge from the observation and the initial interview. Subsequently, participation for the school will entail the researcher attending one regularly scheduled ISSP meeting to record activities. Participation for the parents will entail two additional individual interviews with the researcher. During the ISSP meeting the researcher will maintain field notes only, while both interviews will be audiotaped (for ease of transcribing). Participation in this study will involve no greater risks than are typically experienced in daily life. The benefits of the study are numerous and include significant contributions to teacher training programs, policy development, validation for other parents, and improved approaches/ sensitivity to parents needs in these meetings.

All collected information will be considered confidential. Data will be coded without names, will be kept in a locked cabinet in a locked room, and will be destroyed two years after the publication of the final report. Group findings and/or short, anonymous excerpts, will be published in the final report. No information will be included that will identify the parents, the child, the school, the school district, or staff members. Should the findings of the study be published, either in print or presentation format, no identifying information will be used and safeguards for anonymity will be rigidly adhered to.

The Director of this school board has granted consent for this project and a copy of that letter has been attached.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights to release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. 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. If you have further questions concerning matters related to this research, please contact: David Philpott 737-3506 or Dr. Nancy Marlett 403-220-5657. If you have any questions or issues concerning this project that are not related to the specifics of the research, you may also contact the Research Services Office at 403-220-3782 and ask for Mrs. Patricia Evans.

Participant's Signature

Date

Investigator's Signature

Date

Witness' Signature

Date

A copy of this consent form has been given to you to keep for your records and reference.