

A PHENOMENOLOGICAL STUDY OF STUDENTS'  
EXPERIENCE IN RETURNING TO SCHOOL AFTER  
THE ONSET OF A PSYCHIATRIC ILLNESS

CENTRE FOR NEWFOUNDLAND STUDIES

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MEMORIAL UNIVERSITY OF NEWFOUNDLAND

A Phenomenological Study of Students' Experience  
in Returning to School  
After the Onset of a Psychiatric Illness

by

Marie Catherine Young

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## ABSTRACT

A phenomenological research method was used to explore the experience of individuals in returning to school after the onset of a psychiatric illness. Eight individuals who were diagnosed with a mental illness during their high school years participated in the study. The purpose was to gain a greater understanding of their shared experience. Respondents articulated the struggles they encountered in the school system and relayed their perspectives on the changes needed to provide appropriate and effective programming for students with mental illness. Through qualitative research analysis themes emerged in the following areas:

### Keeping the Secret:

Respondents kept their illness secret because of a lack of public and school awareness and their own pre-conceived notions about mental illness.

### Coping:

Coping with academic demands while dealing with the symptoms of mental illness takes a large amount of energy and results in high absenteeism.

### Feeling Disconnected:

Students with mental illness experience social withdrawal and rejection. To cope they sometimes disconnect from their physical selves, from other people, from their surroundings and from time frames.

### Seeking a Safe Place:

Family is the primary support for individuals with mental illnesses. Students perceive the regular school as lacking the resources required to meet their needs. Alternate schools provide a safe environment.

### Moving Beyond Loss:

Individuals feel a sense of lingering grief over lost school years. Acceptance of the illness can take a long time. Individuals who take control of their lives feel empowered

These findings expand our understanding of the experiences of students and their families as they struggle with the reality of a mental illness. The findings clearly suggest the need for educators, at every level, to increase their knowledge, understanding and sensitivity regarding the experiences of students with mental illness. Increased sensitivity to the struggles of this group will result in improved programming, services, and policies.

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## **Chapter One: Introduction and Background**

A psychiatric disorder is understood by mental health professionals to be a clinically significant pattern of behavior that interferes with major life activities such as working and attending school. Close to 30% of individuals experience some form of mental illness during the course of their lives and prevalence rates in children and adolescence are estimated to be between 15% and 20% (Hales, 1995). Little research, however, has been done on the experiences of students with psychiatric disorders as they move through the school system. In fact, the only educational research relevant to this population exists as a sub-set of the literature on students with emotional behavioral disorders (EBD).

Psychiatric disorders generally require medical intervention and follow up and include significant mental health conditions such as major depression, bipolar disorder, schizophrenia, social phobia and generalized anxiety disorder. Diagnosis of a psychiatric disorder during adolescence alerts the individual and his or her family of the possibility that the illness will be long term and debilitating. Whether onset is sudden or characterized by a gradual and escalating display of symptoms, hospitalization and/or withdrawal from most normal activities is likely to follow. This includes temporary withdrawal from school.

Adolescence is considered a critical period in the active and conscious selection of particular interests, values, and commitments (Kunner, Bosma, & Geert, 2001). A prolonged absence from school during this period deprives the adolescent of developmental experiences, considered critical in the promotion of

identity formation, self-determination, and a sense of normalcy (Bessel, 2001; Weiner, 1992). An adolescent's attempt to return to school after an extended absence is characterized by apprehension and uncertainty. In the aftermath of the original trauma, a return to routine can be a welcomed and/or dreaded experience. Considering the vulnerability of this population of students, a smooth and carefully planned back-to-school transition is critical.

This study consists of phenomenological inquiry and analysis. It explores the nature of students' experiences in returning to school after a prolonged absence due to a psychiatric illness. The study is intended to be descriptive of the student's school related experiences, capturing the nature and essence of the experiences as viewed from the individual's perspective. The study also describes and explores how research participants constructed meaning from their lived experiences.

### **Statement of the Problem**

Students with significant psychiatric disorders are included in the broad educational category of EBD. The larger percentage of students served under this special education category exhibit externalized behaviors often associated with attention deficit with hyperactivity (ADHD), conduct disorder, (CD), and oppositional defiant disorder (ODD), conditions primarily associated with childhood and adolescence (Gresham, 2002). Much of the research and literature in the area of EBD focuses and reflects on issues related to this latter population, while students with more internalized behaviors remain a largely understudied

population. It is a considerable task to extract from the literature those elements that can be generalized to the sub-group of EBD students with significant psychiatric disorders. The limited research targeting students with less disruptive symptoms such as social withdrawal, depression, anxiety, frequent crying, thought distortions, and auditory and visual hallucinations indicates that there is a need for additional study in this area.

The lack of research relating specifically to students with psychiatric disorders is complicated by a lack of consensus regarding the term EBD itself. The appearance in the literature of other labels such as emotional disturbance (ED), behavioral disorder (BD), and serious emotional disturbance (SED), continues to cause confusion among researchers, educators and other professionals (Forness & Kavale, 2000). The term EBD was chosen for use in this study for two reasons: it is receiving growing and widespread support in special education and mental health communities across North America (Forness & Kavale, 2001); and while acknowledging the existence of overlap, it suggests a distinction between two main sub-groups of students with emotional and behavioral disorders.

Inconsistent terminology, the vast differences between the two major sub-groups within the EBD population and the diverse needs of individuals within each sub-group are significant factors which indicate a need for research that clearly defines the population or sub-population being studied.



As a sub-group of the EBD population, students with psychiatric disorders share many of the same discouraging statistics and dismal adult outcomes. Youth with EBD represent the third largest category of students with disabilities (Coleman & Wehman, as cited in Bateman, 1996). Prevalence rates are estimated to be between 12% and 18% (McElaney, Russell, & Barton, 1993; Pumariega & Vance, 1999; Casat, Sobolewski, Gordon, & Rigsby, 1999). In addition, students with EBD have the lowest grade point average of any group of students with disabilities (Bullies, & Davis, 1996; Gunter, & Denny, 1998; Sutherland & Wehby, 2000) and the highest drop out rate reported to be between 40% and 50% (Bateman, 1996; Jones, 1996; Mattison, Spitznagel, & Felix, 1998; McElhaney, Russel, & Barton, 1993; Wood & Cronin, 1999).

As an understudied sub-group of the EBD population, it is crucial that students with psychiatric disorders have their voices heard. Only through an understanding of their unique experiences and diverse needs will effective educational interventions be put into place. This study strives to give voice to this population of students by exploring the nature of their experiences as they attempted to return to school after the onset of a psychiatric illness. Young adults were identified through referrals from mental health agencies and participated in individual interviews on the nature of their shared experience. The study occurred in Newfoundland and Labrador where there is a strong interagency approach to case planning for students with exceptionalities. Through rigorous

phenomenological analysis the essence of participants' experiences were identified in an effort to help guide future practice in the field.

### **Significance of Study**

This study provided a forum for individuals with mental illnesses to tell their stories. Such first hand accounts of living with a mental illness and attempting to reintegrate into society (in this case return to school) after diagnosis and a break in normal activities serves to increase awareness and understanding of the unique challenges these students face. The study provides validation for individuals and families directly affected by mental illness, as they identify with others who have encountered similar struggles. Finally, it identifies effective supports and areas where breakdown between policy and practice occur in the education of students with psychiatric disorders.

The findings of this phenomenological study add to the limited body of literature on the academic and social experiences of high school students with significant psychiatric disorders. The richness of the descriptions gained through this study has implications for educators and mental health professionals. A deeper understanding of the lived experiences of this group provides much needed insight into their unique experiences and diverse needs. The research can be used to help improve programming for this population of students by informing practice and policy and igniting interest in future research in related areas.

### **Researcher's Interest**

In my fifteen-year career I have worked almost exclusively in the area of special education. I have held teaching positions at the primary, elementary, junior high and high school levels. I have worked with students requiring only remedial help and those requiring modified or alternate curriculums. I have worked in teaching positions allocated to serve small groups of students with physical and/or cognitive disabilities. For several years I worked exclusively with students with learning disabilities. This work involved one-on-one teaching, either on an itinerant basis in the student's home school or as part of a pull-out program in a resource center for students with learning disabilities. My work with individuals and small groups gave me the opportunity to work closely with the parents and families of students with disabilities. Through this work I came to reaffirm my strong belief that close communication between school and family is essential for meeting the needs of students with disabilities.

In the last five years I have been working with students with psychiatric disorders who fall in the special educational category of EBD. This work has proved to be the most challenging and most rewarding of my career. I have had the opportunity to witness first hand some of the frustrations inherent in our education system. I have worked closely with parents and listened intently as they voiced their concerns. I have been challenged to remain objective and professional knowing that emotional reactions on my part would not facilitate the student's academic and personal growth. Balancing personal emotions and

professional judgement has meant a constant and thorough evaluation of my values, beliefs, and actions.

In conducting this phenomenological research I continued with this evaluation process. By having a colleague interview me, I was able to formally identify preconceived notions, assumptions, and biases I held regarding the education of students with mental illnesses. (See Appendix D for a full account of this experience).

My experience in all facets of special education leads me to believe that, in spite of advances, the school system is largely failing students with disabilities as well as those who are marginalized for other reasons. My research and experience indicate that it is students with EBD, including those with diagnosed psychiatric disorders who are most at risk. I am passionate and professional when it comes to working with students with psychiatric disorders and their families. I have witnessed the many talents of the students that I have encountered. I have been struck by their insights, moved by their compassion, and humbled by their ability to persevere.

The stories of the individuals in this study need to be heard. It is worth noting that respondents made practically no reference to any type of interagency collaboration as a part of their back to school transition. A lack of awareness, inadequate supports, and inappropriate programming remain major obstacles in educating students with mental illness. It is a difficult journey for these students and one that they are often forced to travel alone.

## **Chapter Two: Literature Review**

### **Introduction**

The literature review is brief, reflecting the lack of research related specifically to students with psychiatric disorders. This void in the literature validated the need for this study and made it necessary for the author to borrow from areas peripheral to the topic. The framework for this study was provided by exploring special education issues that impact on adolescents with psychiatric disorders. Current trends such as interagency case management, individualized programming, and the cascade model of placement options were reviewed. The intent was to gain insight into ways these practices relate to adolescents in their attempt to transition back to school after diagnosis of a psychiatric disorder.

Returning to school after a prolonged absence indicates a milestone in the recovery process of students with psychiatric disorders. Substantial supports from family, school personnel, and other involved agencies are required to ensure a smooth transition. The heterogeneity of the group requires that transition planning be individualized so that appropriate programming and placement needs can be determined. Sample (1998) points out that it is unreasonable to think that one specific intervention, or a pre-packaged plan is going to meet the vast array of individual needs of this population of students.

### **Collaborative Planning**

In Newfoundland and Labrador, there exists a well-developed and strongly articulated model of collaborative planning and case management. Agencies

involved with the student work together to identify strengths and determine the programming and service needs. The multidisciplinary team for adolescents with psychiatric disorders would include representatives from various mental health agencies. Psychiatrists, psychologists, psychiatric nurses and social workers join with home and school in identifying and recording the adolescent's strengths, programming needs, short and long term goals, and required services. The completed document or comprehensive plan is known as the *Individualized Support Services Plan* (ISSP). While the model is well developed in Newfoundland and Labrador, its implementation requires careful monitoring to ensure success.

Interagency collaboration and the integration of services are vital components in the process of providing effective support and successful interventions for students with EBD and their families (Forness, Kavale, & Davanzo, 2002; Lehman, 1997; Oswald, 2002; McElhaney, Russell & Barton; 1993; Pumariega & Vance, 1999). In spite of large scale recognition by special education and mental health professionals of the importance of collaborative planning, there exists much skepticism about its effectiveness in actual educational practice.

Oswald (2002) suggests that "fragmented, uncoordinated services for students with EBD is still a major concern" (p.156). He argues that in spite of attempts at interagency collaboration, parents of students with EBD are still left feeling disempowered. Oswald calls for radical changes to the present system:

... there must be a move toward genuine transdisciplinary collaboration. Such collaboration does not mean that educators merely send a child off to a psychiatrist for a diagnosis and prescription; it does not mean that the psychiatrist merely sends the child back with a bottle of pills (p.156).

Lehman (1997) raises similar concerns stating that systems in place to support students with EBD continue to be "program centered" and "agency focused," rather than student-centered. He reported one study that indicates parents' perceptions of the effectiveness of service coordination may depend upon the personal characteristics of the professionals, the characteristics of the organization in which the professionals work, and the inter-organizational characteristics of the community. When any or all of these were perceived by the parents in Lehman's study to lack a child/family-centered focus, the parents' perceptions of the collaboration effort were negative. Lehman concludes there is a need for further qualitative research to explore students' and parents' perspectives on what constitutes effective comprehensive student and family focused interagency support. In a more recent study in Newfoundland and Labrador, Philpott (2002) documented a clear breakdown between theory and practice. The parents in Philpott's study reported professionals still hold the power in the interagency approach to case management.

Researchers have identified the involvement of a case manager as a method of improving interagency collaboration when working with EBD students. This involves assigning a case manager to facilitate the coordination of multiagency services, link youth and family with community supports and monitor the effectiveness of service delivery (Adelman, 2000; Lehman, 1997; Pumariega & Vance, 1999; Stroul, 1995). Adelman (2000) refers specifically to youth with psychiatric disorders and points out the importance of the case manager being knowledgeable in the area of the illness and possessing the necessary skills to ensure that the comprehensiveness and intensity of the service corresponds to the student's needs.

Others suggest that effective interagency collaboration requires school-based mental health services (Casat, Sobolewski, Gordon, & Rigsby, 1996; Mattison, Spitznagel & Felix, 1998; Pumariega & Vance, 1999; Roeser, 2001; Rylance, 1997; & Wassef, Ingham, Collins, & Mason, 1995). They claim that such school-based services are a preventative measure and a way to provide successful interventions which result in reduced school absenteeism, a decreased drop out rate, a reduced display of externalizing and internalizing symptoms and less involvement with juvenile justice and mental health residential services.

Van Reusen (referenced in Snyder & Shapiro, 1997) stresses the importance of all professionals involved with the student having meaningful and significant input into the student's individualized educational plan. He says that professionals in the various fields need to join with educators, parents, and



students to determine the students' strengths and needs, obtain necessary services, and decide on appropriate strategies and interventions. Van Reusen indicates such an interdisciplinary team should prevent the development of a generic plan that does little to address the programming needs of the individual. The full participation of parents and student is at the heart of interagency case management and is critical in the development of a comprehensive plan that outlines the student's specific programming needs.

### **Programming Needs**

Studies regarding programming needs, best practices, and adult outcomes for students with EBD are increasing, but remain limited. Research related exclusively to the programming needs of the sub-group of students with significant psychiatric disorders is practically non-existent. Attempts to generalize the research findings of studies on the larger group to this sub-population could be viewed as speculative at best.

Academic programming for students with EBD has always raised challenging questions. As a group, students with EBD exhibit performance and skills deficits and low academic achievement (Gunter & Denny, 1998). According to Edward and Chards (2000), little is known about the academic components and instructional approaches that are most effective for students with EBD. These authors suggest that students with EBD need higher-quality academic programs. They conclude academic deficits for students with EBD can be reduced by a

greater degree of teacher engagement and reduced, or well-monitored independent work.

Jones (1996) has a somewhat opposing view to that of Edwards and Chards and suggests that academics are overly emphasized in existing programs for students with EBD. Kauffman et al. (1990) present a similar argument and caution that this heavy emphasis on academics is "at the expense of effective programming for the primary problems for which students were referred" (cited in Jones, 1996, p.54). Both Jones and Kauffman see a need for greater emphasis on environmental and psychosocial interventions. Jones (1996) states that such interventions fall into four major categories: environmental modifications (e.g. changes in teacher's response to student); specific skill building (e.g. problem solving and social skills training); contingency management (e.g. reinforcement, extinction); and insight oriented interventions (e.g. self-awareness).

Consistent with Jones' assertion that interventions involving environmental modifications are needed for students with EBD, Kortering (2002) contends that high school teachers have to change the way that they respond to these students instead of just trying to 'fix' them. Kortering insists that due to the intensive needs of students with EBD, more consideration must be given to such environmental modifications.

Skill development in specific areas is cited in the literature as a necessary component of any program designed to address the psychosocial needs of students with EBD (Bullis & Davis, 1996; Jones, 1996). Some educators,

however, have raised serious doubts about the effectiveness of specific skill training in areas such as anger management, assertiveness training and social skills development. Critics claim that there is little evidence the skills learned in the classroom are transferred to the home and the larger community (Gresham, 2001; Mathur & Rutheford, 1996; Rylance, 1997).

Interventions emphasizing behavior control raise concerns regarding the role of extrinsic and intrinsic motivators, and the suitability of behavior management techniques for all EBD students. For instance, Wassef, Lassiter, and Ingham (1996) comment that emotional and non-disruptive behaviors such as frequent crying, social withdrawal, perfectionism, and obsessive compulsive tendencies do not respond well to the reward and punishment strategy inherent in behavior management interventions, a major component of most programs for students with EBD. They say that careful consideration of individual needs is absolutely imperative to prevent simply 'fitting' students with psychiatric disorders into pre-existing programs with a heavy emphasis on behavior management.

The fourth and final category suggested by Jones is that of insight-oriented interventions. Jones (1996) points out that the basis for all supports for students with EBD is an attempt to empower students by enhancing their sense of personal value, competency, and efficacy. Insight-oriented interventions are intended to increase students' self-awareness and improve self-esteem. For students with significant psychiatric disorders, personal insight and self-

understanding would include an ability to separate self from illness, an important step on the road to personal empowerment.

In addition to curriculum decisions, program planning for students with EBD has to take into account that their behavior fluctuates on a day-to-day and hour-to-hour basis (Wehby, Symons, Canale, 1998). Related to this point is the claim by Wassef, Lassiter, and Ingham (1996) that they have identified teacher and program flexibility as essential components of effective interventions for students with EBD. Mattison and Spitznagel (1998) have found that for students with depressive and anxiety disorders the earlier such interventions are put in place the more favorable the adult outcomes will be.

It is important to determine how great a problem academic and social deficits pose for students with psychiatric disorders. Questions arise as to whether or not existing deficits are the result of factors related to the illness such as debilitating symptoms, the side effects of medication, or extended absences from school. Effective programming for students with psychiatric disorders requires that team members determine the environment most suited to address students' diverse needs, through careful consideration of their unique academic, social, and emotional challenges, taking into account all factors related to the illness that are educationally relevant.

### **Placement Options**

Central to contemporary special education practice is the cascade model of program delivery options. The cascade model, first presented by Reynolds (1962)

outlines the continuum of educational services available to students with exceptionalities. Within this framework educational placement options can be viewed in terms of restrictiveness with regards to the mainstream. Options include full-time general education, part-time resource room placement, self-contained special education unit (either in the school setting or off site), alternate school, residential school, and homebound or hospital schooling (Robertson et al. 1998; & Winzer, 2002). The cascade model has been widely accepted across North America as instrumental in ensuring that students with exceptionalities receive an appropriate education in the most suitable setting.

Recent trends, however, towards a philosophy of inclusive education have resulted in the cascade model being challenged. Inclusion or inclusive education is generally viewed as an attempt to promote a unified educational system, where all students including those with disabilities are educated in the mainstream (Winzer, 2002). It evolved from educational initiatives in the 1980s that sought to eliminate the dual system where "regular education and special education functioned as parallel, rather than integrated enterprises" (Winzer, 1996, p. 70). There is no single model or definition for inclusive education, but many of its proponents see it as both a reflection and an extension of society's commitment to civil rights. Although educators generally acknowledge education in the mainstream is the ideal, the topic of 'full inclusion' is still hotly debated. The argument is fueled by a lack of clarity regarding the term full inclusion and by

fundamental differences concerning views on the need for alternate educational placement options.

Dessent (1996), for example, holds the position that no student including those with disabilities should be placed in segregated classes or special units. Hall (1997) agrees with this position arguing that special schools are inappropriate and that as a form of segregation they are 'culturally deviant' (cited in MacMillan, Gresham, & Forness, 1996).

Demonstrating the polarity of the debate Macmillan, Gresham, and Forness (1996) contend that physical placement in a mainstream setting does not equate to integration into that setting. Allan and Brown (2001) expound on this position and suggest that without a radical overhauling of the school system, a policy of full inclusion for all students would be irresponsible.

Macmillan, Gresham, and Forness (1996) suggest that students with EBD are most often in need of protective settings because the intensive and comprehensive interventions that they require are not possible in the regular classroom. These authors assert that, based upon the concept of individual differences, the civil rights of students with severe EBD are violated if they are forced to attend mainstream classes that do not have the resources to meet their needs.

A more restrictive placement for students with EBD is that of special or alternate schools. A study by Allan and Brown (2001) indicated that students and teachers in special schools for EBD often feel alienated from the mainstream. The

researchers concluded that an increase in formalized links between special schools and the mainstream would be necessary for alternate schools to be seen in a more positive light. According to Allan and Brown, increased awareness of the role of alternate schools is the first step towards improved educational opportunities for EBD students. A recent review of education in Newfoundland and Labrador identified a need for alternate school placements. *Supporting learning: Ministerial panel of education delivery in the classroom* (Government of Newfoundland and Labrador, 2000) recommended the establishment of alternate education programs for students with severe EBD who have difficulty in traditional educational settings.

Robertson et al (1998) found the following factors to be predictive of EBD students' placement in a more restrictive environment: higher age when diagnosed; the existence of externalizing behaviors; severe internalizing symptoms; and poor school attendance, either due to illness or truancy. Given that the population in this study were diagnosed with a severe psychiatric disorder during their adolescent years, the factors identified by Robertson are pertinent. This study provided respondents with a platform to articulate their experiences of these and other factors and an opportunity to describe how they derive meaning from them. This will result in a significant contribution to the literature. Such valuable data should prove useful in assisting with curriculum development and program planning at the secondary level for this population of students.

## Transition

Winzer (2002) states that most definitions of the term transition have in common the concept of a evolutionary process of change involving moving from the familiar to the unfamiliar. She depicts the high school experience as one representing a period of transition for all students as they leave the security of childhood and are faced with making important decisions associated with the responsibilities of adult life.

Adolescents' return to school after the onset of a psychiatric disorder can be seen as a preliminary step in the major life transition to adulthood. Planning for the back-to-school transition can be guided by research findings regarding post-school transitional needs. Maag and Katsuyanni (1998) identified three factors as essential for post-school transition planning, each of which hold relevance for the back-to-school transition of adolescents with psychiatric disorders: the full participation of parent and student in all procedures and decisions regarding the student's placement and program; the need for interagency collaboration; and appropriate and adequate programming in the areas of academics, social skills development, functional living, and vocational instruction.

Program and placement decisions are made through the collaborative effort of a multidisciplinary team, with students and parents playing a central role. In theory, this collaborative process ensures that programming is in place to address the students' unique needs in the environment deemed most suitable. This study will help determine, from participants' experiences and perspectives,



any gaps that exist between theory and practice. It is through the transition process that we see the literature on interagency collaboration, programming needs, placement options, significant psychiatric disorders and emotional/behavioral disorders merge.

The actual transition experience for these students may be complicated by uncontrollable, or unanticipated factors that go beyond program and placement needs and related academic and social deficits. These complex and interrelated factors include: a lack of awareness by teachers and students about mental illness (Diaz-Greenberg et al., 2000); the stigma often associated with mentally ill individuals (Winzer, 2002); the side effects of medication and the impact of medical appointments on school attendance and school performance (Bessel, 2001); and the emotional energy needed to cope with a psychiatric illness on a day to day basis (Vanderstoep, Davis, & Collins, 2000).

Each of the above four factors can have a profound effect on the school experience of students with psychiatric disorders. In a qualitative study, Diaz-Greenberg, et al. (2000) reported that individuals with psychiatric disorders perceived a lack of awareness regarding the nature and seriousness of mental illness as a major problem in high schools that they attended. One individual who was interviewed in the study recalls giving a suicide note to her English teacher and having it returned to her without any attempt, by the teacher, to talk to her or refer her for counselling.

Bessel (2001) studied students with significant health issues and found that medical appointments and medication side effects interfered significantly with school attendance, academic achievement, and social interaction. Often the students in Bessel's study were expected to catch up on missed work. This sometimes proved difficult in light of their medical conditions. Students in this study reported that the understanding and support of a caring teacher was the single most important factor in providing them with positive school experiences after the onset of their illnesses.

According to Vanderstoep, Davis, and Collins (2000) students with significant psychiatric disorders use the emotional energy needed to acquire academic and social skills to deal with debilitating symptoms on a daily basis. McElhaney, Russell, and Barton (1993) refer to the large numbers of children and adolescents who grow up under the "burdensome weight of mental disorders." They state: "Childhood mental disorders can turn even the simplest activities into a struggle. For many youth, getting out of bed each morning and getting dressed for school is a daily battle" (p.1). Clark and Davis (2000) refer to the burden of facing adolescence with the debilitating symptoms of a mental illness as an invisible handicap.

The onset of a psychiatric illness during adolescence and the subsequent attempt to return to school influenced the educational experiences of the individuals in this study. By shedding light on the complexity of their academic,

social, and emotional challenges, this study provides valuable knowledge that will be of significant interest to all of those involved with this population of students.

The various works cited in this literature review demonstrate the need for a clearer understanding of students with psychiatric disorders. Researchers working in this field should be well aware of the varied opinions that exist with respect to adolescents with EBD, and recognize that there is a dearth of literature dealing specifically with the sub-population of students being considered in this study.

### **Chapter Three: Methodology**

Quantitative and qualitative research are both considered valuable methods of educational inquiry aimed at improving education through either knowledge extension, hypothesis testing, or problem solving. The research approach chosen is generally determined by the nature of the research problem, the strengths and interests of the researcher, and a sensitivity to the audience for which the research is intended (Creswell, 2003). Although qualitative and quantitative research are not mutually exclusive, the former is more appropriate for in-depth studies of individuals' activities and experiences, especially when the goal is to explore how participants make sense of these experiences (Silverman, 1997).

Qualitative research, although not new to the social sciences, has seen an explosive increase in popularity over the past three decades. This is in response to a notable shift away from traditional objectivist philosophies such as positivism towards more contemporary theoretical perspectives such as post-modernism, critical theory, and social constructivism (Denzin & Lincoln, 1998). These newer paradigms suggest that truth is the result of perspective and that there exists no objective reality. As Schwandt (1998) puts it: "Knowledge and truth are created, not discovered by mind" (p.236).

Qualitative research, then, assumes multiple realities as suggested in Denzin and Lincoln's (1998) definition: "Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This

means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them..." (p. 3).

Qualitative researchers attribute importance to everything the research participant says regarding the research question. Bogdan (1991) asserts the position that "The qualitative research approach demands that the world be approached with the assumption that nothing is trivial, that everything has the potential of being a clue that might unlock a more comprehensive understanding of what is being studied" (p.30-31).

Within qualitative research methodology, there exists a number of set approaches that have one or more distinguishing features. Phenomenology is a qualitative research approach that emphasizes "the meaning of reality is in essence, in the eyes and minds of the beholders, the way the individuals being studied perceive their experiences" (Wiersma, 1995; p.250). Marshall and Rossman (1995) define phenomenology as "the study of experiences and the way we put them together to develop a world view" (p.82).

Moustaka (1995) distinguishes phenomenology from other qualitative research in that it requires the researcher to set aside or 'bracket' as much as possible, preconceived ideas and judgements about the phenomena being investigated, a process known as epoche. To facilitate this process the researcher was interviewed by a professional colleague on the nature and extent of her experience with students with psychiatric disorders. This interview was audio

taped and transcribed for analysis. This process helped ensure a thorough exploration of prior assumptions and biases held by the researcher and took place before the interviews with participants began.

This study is well suited to a phenomenological orientation as it explores and describes the lived experiences of adolescents in attempting to return to school after the onset of a psychiatric disorder. The study affords the opportunity to view the phenomena of school re-entry, and the essential meanings associated with that phenomena from the perspectives of the adolescents with the researcher playing an active, participant/observer role.

### **Population**

Eight subjects were identified using a unique-case sampling plan. All subjects were 19 years of age or older and had a significant psychiatric diagnosis that interrupted their school experiences following which they attempted to return to school. The diagnoses included the following significant psychiatric illnesses: major clinical depression, generalized anxiety disorder, social phobia, bipolar disorder and schizophrenia. Subjects had all exited the public school system at the time of the study. Three of the study participants had graduated from high school and two of those three held university degrees. Four of the participants were in attendance at alternate schools for adults trying to obtain high school equivalency. One participant had dropped out of high school and was working full time.

Research participants were identified through mental health agencies. Mental health professionals were sent a letter of introduction (Appendix A) informing them of the nature of the study and outlining their role in identifying potential participants. The mental health professionals were asked to identify individuals who met the above criteria and who, in their judgement, were emotionally and intellectually capable of participating in the study. The mental health agency was not asked to supply the researcher with clients' names. The agency distributed to interested and appropriate candidates a letter of introduction and a consent form. (Appendices B and C) These forms contained information outlining the nature of the study, potential harms and benefits, how participants' rights would be protected, limits to confidentiality and the method of data collection. Interested participants contacted the researcher and after consent forms were signed, interviews were scheduled.

The young adults in this study experienced some difficulty recalling specific details and exact time frames regarding the onset of their illness and their attempts to return to school due to the severity of the condition at the time. These difficulties, however, were compensated for by the richness of participants' personal accounts, and the clarity with which they articulated the meanings ascribed to previous experiences, in light of their present day lives. The in-depth interview process helped research participants access former experiences and feelings, and provided a comprehensive picture of the phenomena under investigation.

As a professional, with background and experience in working with individuals with mental illness, the researcher remained aware of the possibility of negative emotional responses. Although the respondents did not require any special assistance during the course of the interviews, a referral would have been made to a mental health professional, or immediate medical assistance would have been obtained if respondents' reaction to the study had warranted such intervention.

### **Ethical Considerations**

All candidates for the study were informed that participation was completely voluntary. They were told of their right to withdraw from the study at any point and the right to refuse to answer any question or discuss any topic with which they were uncomfortable. As indicated in the population section above, the letter of introduction for research participants (Appendix B) clearly outlined the nature of the study, the rights of the participants, possible harms and benefits and limits to confidentiality. The researcher discussed all information in the letter with participant volunteers and asked that the mental health agency do the same when they provided the letter to potential participants. Signed informed consent (Appendix C) was obtained from all participants. Mental health professionals were asked to refer only those individuals who in their judgement were intellectually and mentally capable of participating in the study. Individuals were encouraged to discuss their involvement in the study with support people (e.g. parents, partners, psychiatrists, counsellors) before consenting to participate.



Each interview began with conversation of a general nature. Rapport and trust were established through active listening. The researcher was careful to pay attention to participant needs, preferences, and comfort levels as displayed verbally and non-verbally. All participants were assured of confidentiality (unless dictated by legal limits, which were outlined on the letter of introduction and discussed with participants by the researcher). All participants were assured of anonymity. Coded identities were not used in the text and the names of schools, hospitals, and professionals were not identified. Direct quotes and anecdotal information which could identify the participant were not used in the final report. The letter of introduction to the participant (Appendix B) clearly outlined how data would be secured and later destroyed. Participants were encouraged to question procedures. Interview transcripts and research findings were made available to participants upon request.

### **Data Collection**

The qualitative research interview seeks to describe and understand the meaning of central themes in the life-world of the interviewee (Kvale 1996). The most common method of data collection for a phenomenological study is the in-depth, informal interview. In this study the interactive interview process was successful in generating rich descriptive narratives of students' experiences in returning to school after diagnosis of the illness.

### **Individual Interview**

Mason (1996) presents the notion that even informal and conversational style interviews pose certain challenges and require adequate preparation. He believes that by anticipating possible problems, the investigator is more likely to be capable of maintaining a relaxed and respectful atmosphere during the interview process. Dingwall (1997) agrees with this position and emphasizes the importance of careful planning, stating that the interviewer has to be ready to make choices between breadth and depth and when necessary direct the interview back towards the research problem.

Although an interview guide was used, the direction of the dialogue was largely determined by the respondents themselves. The questions were open ended allowing the research participants room to describe their school re-entry experiences, reflecting and commenting on the nature of the experiences and the meanings ascribed to them. Such flexibility in the interview process afforded the respondents the opportunity to provide richer and more in-depth descriptions.

Eight individuals were interviewed. The interviews lasted approximately ninety minutes and took place in September and October of 2003. Sessions were audio-taped and later transcribed. Follow up by phone for clarification purposes, for which prior approval was granted, was necessary with several participants. Observations (behaviors, body language, non-verbal cues and environment) were documented during each interview and the resulting field notes were analyzed.

An interview that is conversational in style is the most natural, and therefore, least obtrusive and least threatening (Bogdan, 1991). When the study involves sensitive issues, such as the experiences of students with significant psychiatric disorders, it is important that the qualitative researcher create a safe environment for sharing. A degree of emotional investment on the part of the researcher can help create this environment and result in "illuminated data of a greater depth" (Hockey, 1996, p.23). The following was used to guide the dialogue:

1. Describe the nature of your experience in attempting to return to school after the diagnosis/onset of your illness.
2. Describe your academic experiences.
3. Describe your social experiences.
4. Describe any supports that facilitated your re-entry to school.
5. Describe obstacles that impeded your return to school.
6. What do you recommend as necessary supports for other students in similar situations?

Following each interview the researcher engaged in a period of self-reflection through journal writing. This process allowed for assimilation of the data and helped the researcher identify and bracket previously unrecognized biases. In addition to the audio-recording, the researcher maintained jot notes during the interviews. These were analyzed in conjunction with the audiotapes and journal writings. Bogdan, (1991) points out the importance of field notes and reflective

writings in capturing descriptions of people and settings that cannot be captured through audio tape.

Several respondents were contacted by phone, for clarification of certain points they made in their taped interview. Clarification often consisted of valuable information in the form of short anecdotes and clear examples of specific situations, feelings, or themes. Jot notes were taken during these follow-up phone calls.

### **Focus Group**

For triangulation purposes, each participant was invited to partake in a focus group. They were again assured that participation was entirely voluntary. Four of the eight respondents agreed to attend. Subsequently, a meeting was held and the preliminary findings were presented. The respondents listened with enthusiasm and empathy to each others comments and descriptions. Sympathetic looks, head nods and blank stares, silently validated their shared experiences. Certain themes seemed to spark more discussion and emotional reaction within the group than others. Laughter was interspersed with solemn testimonies. The interaction of the focus-group members highlighted and strengthened information gained through the individual interview. As Flick (2002) suggested, the focus group is useful in enriching the data and completing possible gaps in research findings. Cohen, Manion, and Morrison (2000) also recommend the focus group as an effective way of triangulating with other methods of data collection such as the questionnaire or individual interview.

### **Data Analysis**

In qualitative research, data analysis is generally carried out throughout the collection process (Bogdan, 1991; Wiersma, 1995). Data from the researcher's bracketing experience was analyzed before the interviews began. Data from the first interview was analyzed before an interview with the second participant was scheduled. The qualitative research approach demands that all data should initially be viewed as potentially capable of informing a more comprehensive understanding of the phenomena under investigation. As Bogdan (1991) puts it: "Nothing is taken as a given, and no statement escapes scrutiny" (p.31). Moustaka (1995) refers to this procedure of regarding every statement relevant to the research question as equal in value as "horizontalizing the data" (p.118).

Data from field notes and transcribed interviews were organized into categories and sub-categories and emerging themes were identified. Through examination and re-examination of the data, similarities and differences between research participants' subjective realities were identified and patterns were established. The categories and sub-categories were used to generate textual and structural descriptions of the data that could be translated into themes.

### **Limitations of Study**

This research is limited to the views of the participants. Guba and Lincoln (1999) point out that with naturalistic qualitative research "Generalizations are not possible since human behavior is never time or context free" (p.143). However, they state that some transferability of findings to similar contexts may be possible.

The method of inquiry used in this study resulted in rich narrative descriptions and emerging themes, that may be helpful to students, parents, educators and others concerned with the well being of similar populations. The study may also serve as a starting point for additional research on the educational experiences of adolescents with significant psychiatric disorders.

## **Chapter 4: Sharing the Experience**

### **Introduction**

This chapter explores and describes the experience of attending high school after the onset of a psychiatric disorder. All of the respondents stated that they volunteered for the study because they had a desire to tell their stories, and they welcomed the opportunity to have their voices heard. The respondents felt that the sharing of their experiences would help increase understanding and awareness of the challenges that people with mental illness face. The individuals reported that their high school experiences were characterized by confusion, aloneness, and fear. Intrusive thoughts interfered with their daily activities, and academic and social experiences were overshadowed by attempts to cope with the illness on a daily basis.

This chapter represents a summary of the data in its rawest form. Through a process of phenomenological reduction the strength and relevance of the data pertinent to the research aims emerged. Participants' accounts clustered around several major themes which will be organized under the following five headings: Keeping the Secret, Coping, Feeling Disconnected, Seeking a Safe Place, and Moving Beyond Loss. In some cases sub-headings will be used to further organize the material. This will allow the raw data to be presented in a more coherent and comprehensible manner. Chapter 5 will outline more distinctly the themes that emerged in each of the categories. The reader is reminded, however, that with phenomenological research, the themes remain embedded in

the text. A holistic understanding is gained through the stories and personal accounts of the individuals who experienced the phenomenon. The similarities in the language and textural descriptions used by the eight respondents were evident early in the research process. The themes that emerged consisted of considerable overlap, confirming the phenomenological stance that subjective reality can be understood only in context. Due to the sensitive nature of the shared information, coded identities will not be used. Instead, data will be presented to try to exemplify specific themes.

### **Keeping the Secret**

For most of the respondents in this study, secrecy around their illness existed well before the actual diagnosis. Respondents did not necessarily associate their early symptoms with any type of mental illness. In most cases they knew little about such illnesses and experienced guilt and confusion around their feelings of sadness and depression. Not knowing what was happening to them, they tried to cover up their symptoms and resultant feelings. The worse that the symptoms became, the more that individuals wanted to withdraw from family and friends. Feeling that there was something intrinsically wrong with them, they often interpreted their lack of interest, energy, and motivation as a personal defect of character and were reluctant to talk to others about their feelings.

Prior to being diagnosed, individuals were gradually missing more and more time from school. In most cases they would pretend to be physically sick and recalled being creative in their varied excuses. The following statement by



one respondent is an indication of initial attempts to hide feelings of sadness, anxiety, and depression.

*I would always make stuff up, like tell Mom that I had a pain in my back so that I could stay home for as many days as I could get away with.*

*Sometimes I'd say that I had bad cramps from my period or I'd get a lot of mileage out of saying that I had the flu. I just didn't feel comfortable saying what was really wrong. I felt guilty. I guess in time though I just broke. I couldn't keep it all inside any longer.*

With this individual, as with the others, they could not keep their feelings to themselves for too long. Sometimes the parents just "caught on" and sometimes the individuals became so overwhelmed that they "had to tell someone," usually a parent. Once the parents knew what was happening, it took varying lengths of time before medical help was sought. Individuals remember parents telling them that it was just a phase or a part of normal teenage development. Medical help was usually sought only as a last resort, once daily functioning had become so affected that individuals were unable to attend school. Medical intervention and subsequent diagnosis brought only partial relief. Most individuals and their families chose to disclose, to school personnel, as little information as possible regarding the nature of the illness.

The return to school after an absence due the onset of a psychiatric disorder was a highly emotional experience. The illness was characterized by

confusion, shame, fear and a lingering grief. All of these feelings resulted in further secrecy. These individuals were faced with the realization that a once bright and promising future now appeared bleak and uncertain. The individuals and their families had more questions than answers. None of the respondents for this study talked of interagency collaboration playing an important role in their return to school. Their own beliefs around mental illness and their fears around what others would think resulted in respondents dealing separately with the medical profession and school personnel. Interaction between both those groups was minimal.

The respondents recalled the confusion and lack of control they felt in not really knowing what was happening to them. When questioned about her initial diagnosis of bipolar disorder, one respondent replied.

*First, when I was diagnosed it didn't mean anything to me. It was about a year or so before I realized that bipolar was manic depression. When I started to read about the illness it was a big shock. I said 'Oh my God, this is a serious mental illness and one in four people with it kill themselves.' Things started to make a bit more sense. Like the time that I was sitting in my classroom and felt like this dark thundercloud had just rolled in over my head. The not being able to get out of bed in the mornings, the hyper feelings and the suicide attempts were not just normal teenage mood swings. This was not stuff that I wanted to share with friends or teachers, I can tell you that.*

Feelings of confusion, shame, and lack of control were responsible for the silence of another respondent.

*I didn't know what was happening. All of a sudden I became aware that there was a problem. Things just started to spiral out of control As soon as I reached high school, it just happened. I was finally hospitalized and diagnosed with major depression. I was scared and I didn't want people in school to know what was going on. I guess I was afraid of what they would think.*

Feeling depressed through junior and first year high school, one young man suffered in silence. It wasn't until Grade 11 that his parents brought him to see a medical doctor. He described his symptoms as having no energy and feeling sad all the time. After having a battery of physical tests and being asked hundreds of questions, the medical doctor asked the 16 year old what he thought his problem was.

*I was at a loss so I said I suppose that I have mono. It was the only disease I knew that people my age had that made them stay home all the time, made them tired, made them logy and lack energy and made them unhappy. When the mono test came back negative I burst out crying in the doctor's office. I was really embarrassed about that and so was my dad. At that point I still was not taken to a psychiatrist and I was no wiser about my*

*condition. I continued to go to school and tried hide my feelings from everyone there.*

During the onset of the illness, the individuals were confused about what was happening to them and experienced a sense of their minds and bodies being out of control. It was a frightening experience for these young people. Before the illness, they were optimistic about the future and felt that they were immune from harm. They felt in control of their lives and had a clear view of how things were supposed to be. Confusion, low energy, anxiety and depression were not a part of this overall picture. These individuals were not eager to share their new experiences and feelings with others.

As high school students, these individuals were under the impression that very few people knew about their illness. It was their decision and that of their families not to disclose this information unless absolutely necessary. In many cases teachers knew only that students had missed considerable time from school but the nature of the illness was never shared with them. It was more likely that the guidance counsellor would have been informed of the diagnosis, but often parents insisted that it go no further. Respondents concluded that there may have been much speculation about their condition and/or absence from school. It was, however, never talked about openly, by teachers or other students. Respondents recall returning to school carrying with them the secret of their diagnosis, and all the confused feelings and thoughts that went with the illness.

The stigma and stereotyping associated with mental illness took place initially in the minds of the diagnosed students and their families. Many of the respondents could not comment on reactions from teachers and peers because they felt their secret was well guarded. The respondents claimed that their own lack of awareness about mental illness and their assumption that they would be treated differently was responsible for the privacy. The fact that mental illness was not talked about and seemed to be a taboo subject in school, confirmed for the respondents their assumptions that a stigma did indeed exist.

*After I was diagnosed with social phobia and major depression, I didn't tell anyone in school about my illness. I thought if I told people they would probably have misconceptions because of things like TV and movies, and think that I belonged in a mental institution or the psychiatric ward of a hospital and that I was out of my mind. Before I went to a psychiatrist, that's what I would have thought. Because I knew so little about mental illness I assumed other people would know very little too.*

The previous respondent was an avid reader and a movie buff. She enjoyed drama, mystery, suspense, and science fiction. When she was first diagnosed with a psychiatric disorder her thoughts went immediately to characters she had read about and viewed. Suddenly, these characters seemed larger than life and certainly too close to home. She gradually learned to separate fact from

fiction with regards to mental illness, but was not convinced that other people could do the same.

Shame and secrecy also surrounded another young woman's teenage depression.

*I was hospitalized for a serious suicide attempt. Everything was kind of hush hush. After you do it and you're sitting in the hospital you have this period where you feel normal again and you're not exactly proud of what you did. I didn't really want people in school to know that I was on the psychiatric ward or that I had tried to take my own life.*

How could she expect people to understand? She did not understand herself. All she knew was that 'normal' people didn't do things like that and as a typical high school student, if there was one thing that she wanted, it was to be normal. The only chance she had of achieving this goal was to keep her highly personal experiences to herself.

Individuals who had family members with a mental illness had been previously exposed to the stigma. Their decision to remain silent about their own condition was informed by experience, rather than intuition. They were all too familiar with the ignorance and fear that existed in the community. A twenty-one year old female recalls the embarrassment that she felt regarding her older sister's schizophrenia. When she herself was diagnosed with bipolar disorder, she did not want anyone to know.

*I was embarrassed about my sister when I was younger because the majority of people don't know anything about mental illness. There's a real stigma. Because most people are not around it, they just don't know. I didn't tell my friends or anyone at the school. Bipolar people are thought to be crazy. If I told anyone, they would have expected me to do something bizarre.*

Respondents spoke of the amount of energy it took to try and hide the illness. A depression sufferer recalls:

*Nobody knew; teachers, friends, or classmates. I had to hide things all the time. Once, I remember asking the guy at the next locker what period was coming up and what teacher we had. He looked at me kind of funny but I just passed it off by saying something like 'Oh my mind is like a sieve.' I was really conscious of not being with it, not remembering things, and not knowing what was going on around me.*

Like the other respondents, this individual recalls feeling different and being concerned with not fitting in. He "jokingly" comments that he dealt with this in a very calculated manner. His motto became, *If you can't be normal then at least appear normal*. Marveling at his own ingenious plan, he was pleased to announce that he was successful in carrying out the masquerade. He graduated from high school with the rest of his class and managed to receive second degree

honors. However, as he points out, success rarely comes without a price. This respondent vividly recalls the energy it required to fill the varied and competing roles. His whole school life was a façade. He was a gay adolescent trying to appear heterosexual. He was a severely depressed young man trying to appear well. Life seemed meaningless. Nothing was what it seemed to be; nothing was what it should be. With no one to talk to he questioned his values, beliefs and commitments. This respondent became astute at playing the academic, social, and emotional game, knowing he had no real chance of winning.

### **Identity Confusion**

Other respondents could relate to game playing accompanied by the identity confusion. The resulting internal conflict affected their self esteem and strengthened their need to conceal the illness. Grade 11 was a particularly tough year for one female respondent.

*In grade 11, things got worse. It was just a continuous cycle of not measuring up to other people and what they wanted you to be. Never once did anyone stop to ask me who I was or how I felt. Then I realized that I had tried for so long to do and be what others expected that I didn't know who I was. There was nothing to define me. It was like I ceased to exist.*

A male respondent also recalls an undefined self. It was his final year of high school, during which he was preparing to enter the world.



*The very first assignment we got was called 'ME' and you had to write two or three hundred words. It seemed simple enough but I couldn't do it. There was nothing. I didn't know who I was. I didn't know what I wanted to say. All the kids, I found out later, were writing about the day that they were born, the brothers and sisters that they had, things that happened to them, and things that they liked to do. To me 'Me' was a swamp. There was nothing to write. There was nothing to say. I couldn't let other people know how I empty I felt.*

The undefined self was another signal to these individuals that there was something wrong. Their ability as teenagers to reflect on this loss of self indicates that at some level they were able to separate themselves as persons from the illness they had developed. The reference of one respondent to 'Me' as a swamp indicates how mired individuals can become in the vast array of problems that accompany the development of a psychiatric disorder.

### **Coping**

Respondents were apprehensive about returning to school after the onset and diagnosis of their illness. They were concerned about their ability to deal with the illness and cope with academic demands. The illness affected their academic, social, and emotional functioning on a daily basis.

### Coping with the Illness

Coping with the physical and emotional effects of the illness remains fresh in the memory of the respondents. The following description is representative of the type of symptoms experienced by respondents.

*There were days I just couldn't get out of bed. The energy and interest just was not there. I might get up two o'clock in the afternoon, make myself brush my teeth, and get a shower every couple of days. When things got that bad I'd stay home. I couldn't worry about assignments and grades. I was a happy if I managed to feed the dog and get a shower on the same day.*

Similarly another respondent talks about the struggles of living and trying to attend school while coping with a mental illness.

*Maybe there was a fraction of a second when I'd wake up in the morning and feel OK. I'd open my eyes and for a minute all the troubles would be gone. Then suddenly, they'd close in like a storm. The rest of the day would be torture with my feelings and thoughts. Every situation that had a moral question was humungus. I felt responsible for and guilty about all sorts of things from the energy crisis to minor family squabbles. Some days I would just wander around the house looking out the window. With the weight that I had on my shoulders, academic demands had to take a back seat.*

A twenty one year old female recalls the first time she realized that there was something drastically wrong. She was in Grade 11 and had experienced the first signs of depression the summer immediately prior. Getting up to go to school every morning became more and more of a chore.

*It would be 9:30 in the morning and I'd sit there constantly watching the clock, calculating how many more minutes until I could go home. I was thinking this can't be normal counting the minutes to final dismissal at 9:30 in the morning. It scared me. I kept wondering what was wrong with me.*

For the individuals in this study, the physical and emotional symptoms of their illness were not periodic. Their symptoms became all consuming. Even on a good day, they experienced apprehension about what tomorrow might bring. Daily activities became a battle. They found themselves measuring success by the smallest of accomplishments. The heaviness was with them always. Moments of relief were fleeting. Their world had become foreign; their lives unfamiliar.

### **Coping with the Curriculum**

In addition to the inner turmoil, these individuals experienced an anxiety over academic achievement that was not present before the illness. There was a lack of interest in normal daily activities including academics. Work performance suffered as concentration and motivation decreased. The intensity of the

academic pressure served to diminish the back to school experience. In recounting his experience one respondent said:

*I can't really say that I didn't care but academics were not top on my list at that time. It's like if you're physically sick, throwing up, and you got to go to work, the amount of money you're making doesn't really matter. Well, it was the same with me. The side effects of the medication, the shakes, the dry mouth, the bizarre thoughts and all that crap got in the way of my making education a top priority.*

In a similar vein an individual who had been diagnosed with bipolar disorder while in high school recalls:

*Work just wasn't a big priority with me. I was intelligent and I had always been a good student but when the illness hit I just didn't care any more. I didn't want to go to school. I was always worrying about myself, the weird things that were going through my mind. Marks just seemed so unimportant.*

Respondents in the study pointed out that their disinterest in education had nothing to do with an altered value system. These individuals struggled for survival. Their need for security took priority over the need for higher learning and personal growth. In recounting their early school experiences respondents took pride in talking about their intellectual ability and academic achievement. They

used the comparison between their early achievement and subsequent disinterest in learning to emphasize how quickly priorities can change. In relation to keeping their heads above water, the honor roll lost its position of prominence.

Respondents reported drastic changes in their ability to concentrate, after the onset of the illness. They could no longer take it for granted that if they studied for a test, they would remember what they learned. Things that were once second nature for them took tremendous effort. One respondent comments:

*It was such a big change for me. I love to read but I couldn't even read a magazine article much less a history or science text book. I had no concentration. I remember having this test in religion; fill in the blank, 10 blanks. I studied and studied and got a 2 out of 10. I couldn't keep my head together to do what I was supposed to do. Something in my head was stopping me.*

When asked to comment on his academic experience after a stay in the hospital, a twenty four year old young man recalls that the side effects of the medication were causing him to feel drowsy sometimes falling asleep in class.

*I would really try to do the work but I couldn't concentrate. I couldn't stay awake. I remember one time the class was supposed to be reading a novel and the teacher came down and spoke to me. She kind of startled me because I was asleep on my hand. When I told her I was reading my novel, she pointed out that the novel was upside down.*

Students anguished over their inability to concentrate. They described morbid and disturbing thoughts competing with their efforts to absorb academic material. It seemed no matter how hard they tried, the former always won out. It was as if the illness had its own agenda and school work was not a part of the game plan.

With the academic pressure came a sense of being misunderstood. Respondents often experienced teachers as being uncaring and unfair. The following accounts demonstrate the pressures they felt in trying to keep up with the rest of the class:

*There was no taking into account that you were off for a couple of months. You were expected to catch up with the rest of the class. Comments like 'If you don't get enough credits, you're not going to pass and you'll have to come back for an extra year...If you're not careful you are going to mess up your whole future, your whole life, and you're never going to be able to go to university.' The pressure is overwhelming.*

Another student relayed similar perceptions.

*I missed a fair amount of time in Grade 11. It was really hard to catch up. The depression went on the whole year and I missed a lot of assignments. What I did pass in wasn't top quality. I got no special treatment. I never really told teachers what was wrong with me but they had to know that there was something, with such a drastic decline in my*

*grades and work performance. But instead, I think they just thought that I was lazy, that I didn't care.*

The pressure to catch up with missed work and keep up with current curriculum was augmented by the pressure to go to university. Anything else would be considered as a failure. As students with mental illness they felt incapable of making the commitment necessary for a university education. The energy it took to meet high academic standards and stay on the university-bound academic stream was not always available. The comments of one respondent clearly depicts this sentiment.

*To me university was the only route. It was just so ingrained. I found there was a lot of pressure from teachers to go to university. Nobody ever mentioned going to trade school, probably because they were all university people and that's all they knew. There were no classes to gear you towards the trades and I don't mean that in a negative way either. 'Oh Johnny is stupid so he's got to go to trade school.' All that pressure set me up for failure and for me university turned out to be a farce. I had a math learning disability which wasn't diagnosed until I left school. I'm not saying that caused my low self-esteem and depression but it certainly didn't help. I'll never forget my first math class in university. The instructor put more math on the 'wall to wall' chalk board in that one class than I'd ever seen in my entire life. Needless to say my university stay was short.*

The previous respondent had many interests and talents but gave in to the pressure to attend university. For him this decision caused a major setback, fueling further anxiety and disappointment. He struggled in high school and still managed to graduate just one year behind his class. He views his decision to attend university as a mistake, but has since been successful in obtaining a trade. He has worked many years in his field and speaks with a new confidence. He marvels at his latest revelation, that teachers push university not because it is the only option, or the best option, but because it is all that they know.

This awareness of the pressure surrounding post-secondary options was common to many of the respondents. Several shared the fear that they were not going to be able to complete their education and pursue a career.

*It wasn't the schoolwork that scared me the most, it was the constant fear that I may not finish, that because of the depression I would not get my high school. I am just so grateful that I did. But even now, all these years later, I still have dreams that I'm not going to finish school and I wake up in a sweat.*

Respondents were apprehensive about the future. Academic pressures and debilitating symptoms had an negative affect on all aspects of the respondents' lives. Daily functioning was difficult. Social interaction was limited. Respondents began to feel alone in their struggles.



They described feeling not only disconnected from people but from the curriculum, the school space, and even their own bodies. A twenty-one year old female respondent who was diagnosed with major clinical depression at the age of 16 describes what it was like for her.

*I would be so anxious that I couldn't listen. I couldn't concentrate or study so I'd get in class and just kind of zone out. That's the only way I can describe it, just get in class, sit there and completely zone out. I'd just kind of stare off into space, not able to hear anything that's going on around you because you're so absorbed with the anxiety you're feeling because of being back in school and being in that building.*

### **Feeling Disconnected**

With the energy it took to deal with the illness and try to keep up with academic demands, there was little room left for social activity. Individuals felt confused and somewhat ashamed of their thoughts and feelings. They did not think that anyone would understand and reported feeling an intense sense of aloneness.

In their attempts to return to school after the onset of their illness respondents recalled a strong desire to withdraw socially, sometimes accompanied by actual rejection from former friends. As high school students, they felt that they had no where to turn. Even those who acknowledged receiving support from family, friends, and school personnel experienced this alienation. Respondents reported feelings of not being understood by others, and of not

understanding themselves. They could not articulate the type of support that they needed and often kept these feelings inside.

Individuals in this study remember feeling that they were different than other students and were sure that everyone was noticing these differences. Such self-consciousness made it difficult for them to even walk through the school corridors. One individual recalls returning to school after being hospitalized for five weeks for depression.

*It was terrible. I felt like I was an outsider. I'd walk through the halls and I felt like I was one of a kind, an alien. I thought people were looking at my every move. I felt so uncomfortable, like I didn't belong in my own body. It's hard to explain. I didn't know what was going on so I didn't want to associate with anyone. I just thought that people were against me. Even my parents couldn't understand. There was no-one to talk to. There was no where to turn.*

A similar description was given by another respondent as she recalled returning to school after being hospitalized and diagnosed with bipolar disorder. She too felt different than the other students and found herself isolating from former friends.

*Returning to school was just awful. It was like I couldn't blend in. I was like a spoon in the midst of a bunch of forks. I had five pretty good friends but I couldn't even have a conversation with them. I had always wanted to hang*

*out with my friends, but that all changed. I preferred to sit home and watch TV. My friends continued to call me for awhile but I would never want to do anything so gradually they just moved on. I just wanted to lock myself in my room and chill out. I was so insecure. I had nothing.*

A young man who experienced major depression in high school was later diagnosed with schizophrenia. His initial depression coincided with his discovering that he was gay. He does not contribute his high school depression to his sexual orientation. However, his recollections of social rejection and isolation are vivid in his mind.

*In junior high I was very much central to my social group. You might say that I had a position of prominence with my peers. Then, I developed a depression and very early on in puberty, I discovered that I was gay. I thought that I was completely alone in the world. There was no one I could talk to, no one who could relate and there was no way to change any of it. It was a dead end and there was going to be misery for the rest of my life.*

This realization did nothing to facilitate a sense of belonging. The respondent articulates how coping with disconnectedness became ingrained.

*I still had to play the game like I was heterosexual and I still had to pretend like there was nothing wrong. I found myself starting to withdraw from my social group. I remember one experience very clearly. I was sitting home*

*with my sister one Friday night watching our favorite TV show. I was sitting on the couch and I looked down at my dog, my beloved dog who I could never train properly and I thought my God, his life is pointless. All he does is eat, sleep and lie there. What's he got to live for? Then, I turned it on myself. What have I got to live for? All I do is eat, sleep and go to school. I couldn't connect with people any more. I didn't see the point.*

Other individuals were bothered by the feeling that they had to fit in socially. A nineteen year old respondent said that the pressure of having to be like everyone else was unbearable after the depression hit. Early in Grade 11 she recalls deciding that she had enough.

*I was so uncomfortable in school. I hated dressing up and putting make up on and doing my hair. It's just not me. I always felt isolated. I had nothing to say. I'd rather stay home and read a book. After I was diagnosed with major depression and social phobia, I tried going back to school several times but I would only last a few days. I couldn't bear it. It wore me out, trying to fit in like that but not really wanting to. I just wasn't like everyone else.*

## **Rejection**

Several respondents, in discussing their feelings of disconnectedness, stated how these negative feelings were exacerbated by blatant rejection. While

respondents were aware that their perceptions did not always coincide with reality, they also realized that, at times, it was reality that fueled their perceptions. This was particularly poignant in peer interactions.

*After being out of school for awhile because of my depression, I basically lost all my friends. I just felt thrown aside because if you're not there, you're not part of the group any more. It seemed that the few friends that I told about my illness just got a kick out of it, laughed about it, and carried on with their lives, forgetting about me. No one would say anything to my face but I could sense them talking about me behind my back.*

A 28 year old woman recounts one very painful social experience after being hospitalized for a serious suicide attempt.

*One of my best friends used my suicide attempt as an excuse to transfer to another school. She told her parents that if they didn't transfer her she was going to do what I had done. You know teenage drama. After she moved on we never communicated again. That really hurt because she was the only friend that I had let visit me in the hospital. I never thought anything would change when she transferred but she stopped wanting to hang out with me, associate with me and that's what hurt. Now I really had no one to talk to.*

A 21 year old male who had been doing street drugs when he was diagnosed with a psychosis spent many months in the hospital. When he came out he stayed clean of all street drugs, but was on medication to help him deal with his paranoia. He says he had always been popular in school and was well liked by everyone, students and teachers alike. But when he got out of hospital things were different:

*I got some pretty harsh treatment. I found out everyone knew where I had been. I didn't think anyone would find out but they did and they started calling me retard and stuff like that. I was hearing voices. I couldn't even ride the bus. Excuse my French but I was really "f" d up. I felt so alone. I got really depressed.*

Feeling increasingly disconnected from others, respondents found it more and more difficult to cope with the illness. Social withdrawal and rejection had become their silent realities. Daily functioning could no longer be taken for granted. Respondents sought refuge from familiar people and places.

### **Seeking a Safe Place**

The respondents in this study found themselves attending school while trying to cope (secretly) with the sometimes debilitating symptoms of a mental illness and deal with their growing sense of disconnectedness. Academic demands were overwhelming for some of these individuals and social interaction proved too challenging for them all. The school was largely unable to meet their

needs for academic achievement, social development, and personal growth. The school building itself had become their nemesis. It represented intense feelings of alienation. Secrecy, academic pressure, and social isolation characterized their high school experiences. High absenteeism and day dreaming were attempts to cope with the ordeal. In the process of trying to deal with the illness students hoped for support from home and school. Feeling awkward, self conscious and out of place students sought a place of refuge. With the exception of family support, they encountered further disillusionment.

### **Family Support**

Respondents named family support as the single most important factor in helping them cope with their illness during their high school years. Although individuals commented on the frustration they felt, when they realized family members did not fully understand what they were going through, they never doubted their love and support. Several respondents attributed their academic success and high school completion solely to support from parents and other family members. They also spoke strongly about the importance of the emotional support they received from family members.

*I'm afraid that I fell through a lot of the cracks in school. If I didn't have the family support I had I wouldn't have made it. I can't imagine what it would be like to go through what I went through without strong family support, to have to do it on your own.*

Another respondent remembers the onset of his depression. At first he tried to deal with it on his own. But when it got too bad he told his mother and eventually, after the onset of a second depression, the secret was shared with the father.

*My family, my mother in particular, was a great support when I first got depressed and then when my second depression hit, my dad was supportive, at least to the extent he could be. Throughout the course of my illness, my family has always been there for me. We're not the type to go watch On Golden Pond together but we're still a family and that has been the most deciding factor in the success of my life. As far as I am concerned families are the number one support givers for people with mental illnesses. It's not doctors, nurses, teachers, friends, it is the family.*

One academically strong respondent developed bipolar disorder and quickly lost all interest in her studies. Her concentration was affected and she, like many others, struggled to sustain her place academically while continuing to guard "the secret." She attributes her successful completion of high school solely to her parents, both of whom were professionals.

*I had to work hard to get good marks but I guess that I was luckier than most. Both my parents were well educated and were capable of giving me the help I needed. I had to be pushed and I needed help in the sciences. Without the home support I would not have done so well. Also, I was in the*



*hospital when our class was preparing for final exams. Mom and Dad had to go to the school and really fight for me. Some of my grades weren't as high as they should have been because certain teachers held the time I missed against me. Lucky for me Mom and Dad straightened that out.*

For these individuals, the reliance on family was strengthened by the sad realization that previous friends were no longer a source of support. Respondents' worlds became smaller as their social networks faded. They responded to this loss by withdrawing further into self. The painful reality of peer rejection left them even more guarded than before. Family support became their lifeline.

### **Medical Support**

Respondents indicated that, in their search for safety, they received limited and less than adequate support from the medical profession. Although respondents felt respect for the medical people who diagnosed and helped manage their illness, they raised concerns about medication being the only treatment. There was little if any communication between the school and medical personnel. Respondents saw their illness as unrelated to their educational programs and worked actively to keep it that way in order to maintain the secret. While acknowledging attempts by professionals to help them in specific areas, there was no sense that a collaborative interagency approach was ever used, or even desired. All references to assistance given by medical personnel concerned

pharmaceutical treatment or assistance with alternate school, and post-secondary school placements.

*The first psychiatrist I went to gave me some pills. He didn't explain what was wrong with me or exactly what the pills were for. I just took the pills and I felt blah. Then I went to a female psychiatrist and she explained to me that I had bipolar disorder and told me what the pills were supposed to do for me. She even helped me get back into an adult school setting to upgrade my high school marks.*

A young woman who suffered from major depression during her high school years enjoyed her visits to her psychiatrist and psychologist. She liked both of them and looked forward to the weekly chats. She was never quite sure that the pills were helping her and in spite of her regular sessions with these two professionals she was skeptical about the effectiveness of the treatment.

*My psychiatrist monitored my medication and my psychologist tried to get behind the reasons that I was having so many problems at school. I liked both of them but nothing changed. High school was still unbearable.*

One high school graduate with chronic depression describes how he perceives the role of his psychiatrist.

*My psychiatrist is a good fellow but I only go to him for pills. That's the way it's always been, ever since high school. I don't really get to talk to him. He*

*seems too busy. He started me on pills ten years ago but I'd really like to get off. It seems that he dismisses that idea every time I mention it. Maybe it would help if he worked with me in some kind of therapeutic role... God knows I'm not getting any better on these pills. They didn't help the depression in high school and I don't think that they're helping now.*

Respondents were disappointed in the role played by the medical caregivers. Not wanting to appear unappreciative or disloyal, they were quick to point out the redeeming qualities of their psychiatrists and psychologists. They respected and enjoyed these people but at some level expected, or at least hoped for more. If the "experts" in the field didn't have the answers, it was easy for the respondents to lose faith in their education, in their future, and in themselves.

Respondents were frustrated, seeing medication as a "Band-Aid" type solution, for wounds that were not superficial. Neither, could they fully accept the medical explanation of a chemical imbalance. As with the disappointment of realizing that peers provided little safety, the limited support and safety available from the experts, made them rely more exclusively on the family.

### **School Support**

Although school supports were affected by the level of secrecy with which respondents chose to deal with their illness, there was considerable agreement, among respondents, regarding what was available and what was missing during

their high school years. In discussing the search for safety within the school, sub-themes quickly emerged.

**Teacher support.** Respondents felt that understanding, caring, and open-minded teachers were necessary in dealing with students with psychiatric disorders. Yet, discussions of teacher support was dominated by a failure of the profession to recognize and respond to their overall needs.

*Whatever chance there would be of approaching a teacher, it would have to be someone who was caring. I always remember the teachers who smiled, who made a little joke, who listened to what I had to say. It was really important for me to be acknowledged. Some teachers don't even say hello to the class before they start writing on the chalk board. I think it's so important for teachers to show they care, that it's not just a job for them.*

While some respondents were grateful for their academic help and concern they received from teachers, most were angry.

*I remember my marks started to drop all of a sudden. This one teacher started writing sarcastic remarks on my tests. He never once came down to me and said 'Is there any reason that you're not doing as well as usual?' Or 'You seem to be looking out the window a lot, are you preoccupied with anything?' He was a math teacher and he made no effort.*

On further questioning, this student visibly displayed the intensity of his feelings.

*I felt angry. 'You bastard, you don't know anything about me, so F off and take your math tests and shove them. That type of language would come to me all the time but I never said anything to him. He didn't have the right to judge me. He did not know what I was going through and he did not make the effort. Maybe at the time I wouldn't have opened up anyway but he didn't make the effort. None of them did. Nobody made an effort, never, ever, ever, ever.*

Whether respondents perceived their teachers as caring and concerned or non-caring and detached, the result was generally the same. They were reluctant to approach teachers to talk about their illness. Being absorbed with their own physical and emotional state at the time, students experienced a full array of emotions, from surprise and disappointment to resentment and anger, because they felt teachers were not intuitive enough or concerned enough to initiate contact and discussion.

**Guidance counsellors.** While a sense of safety did not come from respondents dealings with teachers, neither was support readily available from school counsellors. Although some respondents talked about guidance counsellors helping them arrange for academic accommodations, not one reported receiving emotional support, or counselling regarding their illness. To

some of these respondents, that did not seem unusual at the time, but upon reflection a theme quickly emerged regarding the role of the guidance counsellor.

*When I was in high school, the guidance counsellor was practically invisible. He came in once at the beginning of the year and he said if we needed any help with our plans to go to university, come and see him. He could have been more useful if he had done more than just sit down with his university calendars. I think the guidance counsellor should have been doing more to increase awareness of mental illness. Maybe I would have gone to see him if he had been more visible around the school or if I had heard him talk about anything other than university.*

Another student responded to the question, "Did you ever go to the guidance counsellor just to talk about your illness or how you were feeling?"

*No, generally I never got the feeling that the guidance counsellor was really set up for anything like that. The posters on the walls were all about universities and career exploration. There was nothing there about mental illness. There was nothing about any kind of problems. The guidance counsellor was meant to guide you towards your career. There was nothing about mental illness. It was the thing they didn't want to talk about.*

When asked if she received any support from the school guidance counsellor after being hospitalized for her suicide attempt a twenty five year old woman responded.

*No, and it's kind of weird. As far as I know she is the only one in the school who knew why I was in the hospital. My parents went in to talk to her so she knew all about it. But it's funny, she never, ever once stopped me and asked me how I was doing, or how I felt. Actually, at the time that didn't strike me as strange but it does now. It's weird. She was the guidance counsellor, you think she would have at least asked how I was doing.*

Respondents perceived the role of the guidance counsellor as very narrow. Seemingly endless talks by counsellors about university admittance requirements, and displays of university posters on the walls served as a constant reminder to respondents that they were not a part of the high school culture. It added to the pressure they felt to 'catch up and keep up', and further enhanced a sense of disconnectedness.

The lack of safety and support at school and the limited support from the medical profession overtaxed the support available at home. This resulted in many of the respondents dropping out of school or finding alternate arrangements for continuing their education.

**Alternate schools.** Five of the respondents attended an alternate school of some form. These individuals reported finding a sense of safety in the smaller

school setting. Although their struggles with mental illness remained, there were some notable differences in their experience of the smaller rather than the mainstream school. One individual credits her attendance at two separate alternate schools with making it possible for her to continue her education. In Grade 11, when she could no longer cope with the high school environment she was given the opportunity to attend an alternate school within the public school system.

*I really liked it there. What a difference! It wasn't formal, everyone was friendly, students and teachers. There were no bullies, no smart asses. I didn't have to dress a certain way, wear make-up, fuss with my hair. You could talk openly about your illness and your feelings. There were no big classes so I didn't feel any anxiety. There was hardly any stress. Learning was fun, which I always thought it should be any way.*

Respondents reported feeling comfortable in the alternate school setting because of the flexibility and reduced pressure. Most described it as a positive experience with no disadvantages. One respondent, however, raised concerns about the stigma attached to alternate schools. She felt that she missed out on the social interaction of the high school experience.

*The staff at the alternate school were great and didn't treat you like you were children. You could get a lot of individualized help because there were only 4 or 5 students in a class. But still, there was a stigma attached*



*to the fact that you were not going to the 'normal school system.' It was awkward trying to explain to people that I went to a school designed for the mentally ill. Also, you are very, very sheltered in these kind of schools. I think that a happy medium is needed between the small separate school and the regular high school.*

Several respondents dropped out of high school and later entered an alternate school for adults with diagnosed mental illnesses, where they were able to work towards a high school equivalency diploma. These individuals spoke highly about the setting. All three believed the regular school system could not work for them and were adamant that more smaller schools were needed. Respondents reported they felt a sense of connection, in the alternate school that was missing from their regular high school experience.

*After I dropped out of high school, I went to an alternate school for adults, not just for people with mental illness. It was great, the teachers, the students, and the workload. That school and the one I'm in now, which is just for people with mental illnesses really changed my life. Just having a small group to confide in increased my confidence so much. In the smaller school you can take baby steps. In class you are more at ease, you can laugh easier, you are more prone to ask questions. It is just an overall better learning environment. When everyone in the school has an illness, it's even better again. You usually get to know these individuals*

*outside the school. You can joke with each other about your illness. What used to be so shameful can be joked about. You feel comfortable because everyone understands.*

### **Moving Beyond Loss**

Respondents were at different stages of acceptance with regards to their illness. As they reflected on their high school experience several of them expressed a deep sense of loss. This seemed most prominent in individuals who had graduated from their neighborhood school. However, one individual who left high school, enrolled in alternate school settings but never completed a high school program, also expressed a profound sense of loss over her high school years.

The sadness and grief that respondents described went beyond their depression. It came from missing the joys of high school life and feeling disengaged from the high school culture. As students, they were aware of how much they were missing and they knew that they would never be able to get those years back .

*I've been out of high school four years. I never finished. I'm working full time now. When I was in high school I missed a lot of time because of the depression. You know everyone is always talking about their high school experiences, I don't really have any. Everyone has memories of parties, going out with friends lunch time to have a cigarette, just hanging out and*

*gossiping, I missed out on all that stuff. And there's nothing I can do to get it back. You can't go back in time and do it over again.*

For some the grief and pain was accompanied by resentment and anger over all that was lost. A twenty-five year old female respondent with a university degree and a post graduate diploma describes her feelings.

*In high school I was constantly depressed and I lost all those years that were supposed to be years spent going out with friends, drinking, and having boyfriends. I lost all of it. Do you know how hard it is to get your life back after when in your formative years, all you've known is depression and mental illness. It's very hard... I knew how much I was missing but I always thought that things were going to be better. But now I feel resentful and I feel angry about losing those years. There is a lot of pain. I don't know if I'll ever get past it.*

When asked what his high school experience was like a young man in his 30s who was successful in completing high school responded in a similar way.

*For me high school was a living nightmare. I didn't even go to my grad. All my energy was needed just to stay afloat. Extra curricular activities were out of the question. I feel sad about that but I had all I could do to keep up with my school work. You hear people say that their high school years*

*were the best years of their lives but it wasn't that way for me. I missed so much and I'll never get the chance again.*

There were other respondents who expressed a desire to put the past behind them. These individuals were focused on current undertakings and talked about being grounded in who they were. Knowing that they had been affected by their past, they did not want to be limited by it. One respondent shared that if she finds herself falling back into the same pattern of insecurity and self-doubt she reminds herself of how far she has come.

*Sometimes when I think back to my high school years, I fall back into being insecure, but then I remind myself that that's who I was then, but this is who I am now. I refuse to stay in the trap of regretting the past. I'm still young, yet high school seems like a whole life time away. I have so much I want to do, so much I know I can do in spite of my illness.*

With a new confidence and sense of control over her life, this respondent felt empowered to look forward to the future, set goals, and as she enthusiastically puts it, "make up for lost time."

Another young woman was excited about her recent acceptance to a two year college program. She successfully completed her final high school credits in a high school equivalency program. She talked about the empowerment she felt when she decided to leave the regular high school.

*Everyone tried to talk me out of it, including my family, especially my father. But I was so sure of myself. Every day of high school had been awful. It wasn't until I made that decision, took charge of my life that I knew I was going to be OK.*

### **Summary**

Respondents gave similar accounts of their high school experiences and were eager to share their stories. The message was clear. The individuals in this study spent their formative years in an uphill battle and had to rely mainly on their inner resources, and their families, to overcome many obstacles. Confusion, secrecy, isolation, and despair challenged their strength and determination. Alone on their arduous journey the respondents found some solace in knowing that they had the support of their families. Confused and afraid, respondents chose to remain silent regarding thoughts and behaviors related to the illness. They struggled daily with physical and emotional distress. Feeling disconnected from people and places, they withdrew into the confines of their own minds.

As students, respondents found themselves disengaging from the high school culture. There was a clear absence of supports and sense of teacher concern to help them feel connected. Absenteeism was high. At times, students returned to hospital rather than deal with the uncomfortable feelings that resulted from school attendance. There was a blatant and profound failure of the system to support or even recognize them. For five of these individuals the pain was too great. They left their neighborhood schools and sooner or later found a sense of

safety in an alternate school setting. This proved to be a positive experience and, for some of the respondents the first step to empowerment and control.

Acceptance of a mental illness does not come with the diagnosis. Individuals, while grieving the loss of their high school years, are at various stages of moving on.

## **Chapter 5: Reflections and Implications**

Keeping in mind the themes that emerged in Chapter Four can be more fully understood within the context of the respondents' stories, I will now present them in a more discrete manner. Outlining the themes will provide the clarity needed to recognize the implications that the results of this study have for individuals with mental illnesses, their families, educators, researchers and other professionals in the field.

### **Reflections on the Themes**

These themes and sub-themes emerged from the respondents' stories and are examined in light of the literature reviewed in chapter two.

#### **Keeping the Secret**

- Students and their families felt that they were not adequately informed by the medical profession about the illness.
- Students' confusion about their illness and their own preconceived notions resulted in non-disclosure to friends and teachers.
- Lack of public and school awareness, existing myths, and stigma added to students' shame and impeded their attempts to return to school.
- Students felt that school staff were not equipped to deal with mental illness. It was not talked about in the school.

#### **Coping**

- Coping with a mental illness requires large amounts of energy.
- Students struggle to maintain normality.

- Academic pressure limits their ability to cope.
- Students create safety by zoning out mentally.
- High absenteeism reflects a need to escape from the school environment.

### **Feeling Disconnected**

- Students experience a strong sense of aloneness or separateness, feeling disconnected from their bodies, from people, from their surroundings and from time frames.
- Not feeling understood by friends, teachers, guidance counsellors and sometimes family members, students withdrew into self.
- Students with mental illnesses sometimes face social rejection.

### **Seeking a Safe Place**

- Family is the primary support for individuals with mental illnesses
- Students felt that schools lacked the awareness, resources and supports to deal effectively with their needs.
- Students reported that alternate school settings provided a safe place for them.

### **Moving Beyond Loss**

- Acceptance of an illness can take a long time.
- Students have to make difficult decisions about their education and careers as a result of the illness.
- Respondents reported a sense of lingering grief over lost high school years



- Those who take control of their lives feel empowered in spite of their struggles.

## **Discussion**

### **Keeping the Secret**

The experiences of the individuals in this study concur with the literature explored in Chapter Two regarding the lack of awareness and stigma associated with a mental illness (Diaz-Greenberg, Thousand, Cardelle-Elawar & Nevin, 2002; Winzer, 1996). Respondents in this study added to the knowledge by stating that their own preconceived notions, and that of their families, prevented them from disclosing information to school personnel. The respondents describe the confusion, shame, and fear, that they experienced after being diagnosed with a mental illness during their high school years. Their own lack of awareness, misconceptions, and stereotypical beliefs inhibited them from discussing their illness with teachers, guidance counsellors, and friends.

Feeling uninformed about the illness and prognosis, individuals and their families kept silent. They assumed that they would be treated differently, and in many cases partial disclosure proved their assumptions to be correct.

Communication, interagency collaboration, and integration of services are cited as essential components in the process of providing effective support for students with any form of EBD, including psychiatric disorders. (Forness, Kavale, & Davanzo, 2002; Lehman, 1997; Oswald, 2002; McElhaney, Russell & Barton;1993; Pumariega & Vance, 1999). The individuals, however, in this study

clearly report that communication and collaboration was limited or non-existent in their back to school transition. Consequently, respondents struggled academically and emotionally. Like the students in Bessel's (2001) study, who missed considerable time because of significant health issues, respondents were expected to keep up with missed work. Teachers, not knowing the details surrounding students' absences, were reluctant to make allowances for academic underachievement. Students felt the pressure, but suffered in silence. The teacher and program flexibility promoted by Wassef, Lassiter, Symons, and Canale, (1998) as essential for effective intervention of students with EBD was virtually non-existent.

Withdrawal from former friends and social groups was both symptomatic of the illness and a source of additional anguish. Respondents reported that "keeping the secret" and trying to appear normal in front of their peers combined with academic demands, required large amounts of unavailable energy. In guarding their secret, they became more and more disengaged.

### **Coping**

The academic struggles, social withdrawal and low energy combined to make school an unpleasant and threatening place for these individuals. The daily routine became an increasing burden and respondents reported getting up in the mornings as their greatest challenge. This coincides with the literature of McElhaney, Russell and Barton, (1993). They discuss how seemingly ordinary activities such as getting out of bed and getting dressed for school are major

undertaking for students with psychiatric disorders. Despite the existence of this knowledge, none of the respondents felt that service providers helped them deal with their reality. Respondents talked about feeling exhausted all the time as high school students and not having the energy to balance school work, social activities, and personal interests. Again, this depletion of energy is well-documented in the literature. Vanderstoep, Daves and Collins (2002) articulate that such energy depletion and lack of motivation when they make reference to the emotional energy needed to deal with the debilitating symptoms of a mental illness. McElhaney, Russell and Barton (1993) concur and speak of the "burdensome weight of mental disorders" as being overwhelming for children and adolescents. Yet such existing knowledge did not affect programming for these students.

The individuals in this study returned to school without any supports in place, and for the most part without the benefit of school personnel being informed about their illness. As students, these individuals were alone in their struggles to keep up with academics, to appear normal, and to deal with debilitating symptoms on a daily basis.

In the public school system there was no programming geared toward psychosocial insight-oriented interventions which Jones (1996), and Kauffman (1998) suggest are necessary to help students cope with living with a mental illness. The experience of these students, certainly, the absence of well-documented supports raises questions for the knowledge base of school staff.

Respondents felt that teachers were not trained and the high school was not equipped to help them in their struggles. As a result, on days that they were unable to cope, students would opt to remain at home. Their high absenteeism was more of a survival tactic than an indication of a disinterest in learning. Some students found relief in street drugs while others removed themselves mentally from the classroom setting by daydreaming, or just zoning out. Absenteeism, lack of concentration, day dreaming, and clock watching were seen by teachers as a lack of motivation.

### **Feeling Disconnected**

Participants reported that the school and education system was not conducive with, or supportive of their way of being in the world. As a result, a feeling of disconnectedness from the school, from their peer group, from actual time, and from their physical selves began to emerge. Van Manen (2003) states that there are four fundamental existential themes that seem to pervade the life world of all human beings and keep them connected to their surroundings. In helping understand the essence of these students' disconnectedness, a discussion of these existential themes becomes useful. While they clearly overlap, discussing them individually affords a holistic view of the phenomenon of returning to school after the onset of a psychiatric disorder.

Van Manen outlines these themes as spatiality (lived space), corporeality (lived body), temporality (lived time), and relationality (lived other).

### **Spatiality (Lived Space)**

Van Manen (2003) posits that lived space (spatiality) is felt space. The way students experience the lived space of school depend upon the degree of comfort, enthusiasm, and security felt within the surrounding walls. Respondents in this study gave compelling descriptions of the way their school space was experienced by them. They described long and endless hallways and sterile walls, with one individual referring to his high school as an empty barracks. The tone and the blank stare of another respondent painted a bleak picture as she referred to her high school as "that building." She shuddered as she commented about still being haunted by the memory of the front doors of her school. Respondents projected painful and lonely feelings on to the space in which those feelings occurred. For them, the school was not a safe place. The building itself became the enemy.

Students found refuge in the sanctuary of their bedrooms, resulting in high absenteeism. They reported that they would fake being sick, but did not equate their desire to stay home with their illness. Instead, it was a need for a space where they could feel free to be who and what they were. During school hours, individuals would become absorbed in their own thoughts and mentally disconnect from the unpleasant school surroundings.

### **Corporeality (Lived Body)**

As students, these individuals' experience of lived body was characterized by extreme awkwardness and a need to blend in and go unnoticed. Try as they might, however, this was not their experience. In this already hostile school space, they described feeling increasingly uncomfortable and self-conscious. Several of them commented that they felt as if they did not belong in their own bodies. One respondent spoke of watching himself being stared at as he walked down the corridor, wondering at the time, if he was having an out of body experience. In school, respondents coped by daydreaming often feeling that they had the ability to leave their bodies, removing themselves from their physical state.

Feeling paranoid, self-conscious, and physically threatened, respondents limited their involvement in the community. Trips to the shopping mall, library, or movie theatre became less and less frequent. One individual recalled that he was afraid to ride the bus because he felt that people were staring at him. Respondents reported physical symptoms such as frequent heart palpitations, sweating palms, and headaches. It was through the 'zoning out' or day dreaming, that respondents felt that the unpleasant body sensations disappeared, or decreased.

### **Relationality (Lived Other)**

Van Manen (2003) proposes that from the larger existential sense it is the experience of the "other" or the communal which gives people a sense of purpose

and meaning in life. The respondents in this study felt isolated, rejected, and alone. Their disconnectedness extended to an inability to just "be" with others, including former friends. Their sense of being different was so strong that social withdrawal became a need rather than a choice. Respondents spoke of not being able to talk to friends, teachers, and in some cases family members, especially about their illness. They no longer experienced the "other" as capable of understanding. They lost enthusiasm for past interests and could no longer connect to others on a deep and personal level.

Respondents' lack of connection and feelings of safety with others including teachers, counsellors, and peers affected their interest in normal daily activities. School work, grooming, and even getting out of bed in the mornings were no longer perceived as important. This lack of interest in connecting with others resulted in a gradual withdrawal, a giving up. For several of the respondents, this sense of being discovered as an "other" dominated their lives, until they found the safety of the alternate school. There in spite of their illness and all the accompanying characteristics, they discovered "others" with whom they could relate, with who they could connect.

### **Temporality (Lived Time)**

According to Van Manen (2003) lived time is subjective time, as well as a temporal way of being in the world. The respondents in this study spoke of the overwhelming pressure to 'catch up' and 'keep up' with assigned work, anxiously aware of deadlines, future and past. Their compelling descriptions of clock-

watching, zoning out, and daydreaming are representative of the subjective ways they experienced the speeding up or slowing down of time, in an effort to cope with classroom activities.

As high school students, respondents' temporal way of being in the world lacked the hopeful anticipation of a young person filled with future plans and dreams. Typically, respondents described an intense fear of the future, dreading that it would bring the same emptiness as their high school years. Pressure to attend post-secondary institutions served to fuel the fear of future disappointment and failure.

In telling their stories and reflecting on their attempts to come to grip with their illness, the adult respondents are still burdened by past temporality. They grieve those "lost years", fully aware that what was supposed to be the best years of their lives have been stolen and can never be reclaimed. Their grief, becoming a integral part of their reality, demands that they challenge themselves, time and time again to accept, to manage and move beyond.

When viewed in light of the high school experiences of the respondents in this study, the existential themes put forth by Van Manen (2002) have educational relevance. The feelings of disconnectedness experienced by these individuals call for increased teacher awareness and sensitivity. Training should emphasize ways to facilitate peer-support and lessen academic pressure. The review of the literature combined with the personal accounts of the respondents suggests that the necessary knowledge already exists but that teacher sensitivity is limited.



### **Seeking a Safe Place**

This exhausting and often futile struggle to cope, coupled with feelings of disconnectedness resulted in a search for safety. Several individuals reached the point where they could no longer stay in their neighborhood school. After varying lengths of time out of school, these students enrolled in an alternate school setting, either adult-based or within the public school system. There they found safety and support in the more individualized learning environment. There they felt understood and the sense of aloneness, discomfort, and pressure was minimized. As a result, absenteeism declined and academic achievement and social interaction increased.

Consistently, students stated that the regular school system could never meet their needs and that increased awareness about mental illness, additional resources, and extra supports would not be enough. They contended that the nature of their illness was not compatible with the strict regimen of the public school system. Like MacMillan, Gresham and Forness (1996), these individuals believed that students with severe emotional behavioral disorders require intensive and comprehensive interventions that are not possible in current classrooms. The respondents in the study adhered to the opinion that smaller schools are essential for the education of students with mental illnesses. They were equally clear in articulating, as did Allan and Brown (2001) that much public education is needed to challenge the stigma that is often associated with such facilities.

### **Moving Beyond Loss**

The respondents in the study reported varying degrees of acceptance with regard to their illness. They talked about the difficult decisions that they had to make around education and career options. Some of the respondents grieved lost opportunities while others were angry about their continued struggle to obtain and maintain employment. All but two of the respondents stated that they felt a sense of grief over what they considered to be lost years. They each commented at various times during the interview that it was still painful to reflect on those lost years, knowing that they could never get them back.

In reflecting on their educational experiences, respondents reported that functional living and vocational instruction was not a part of their program in either the public school or the alternate school setting. Again this experience is contrary to what is known in the literature. Maag and Katsuyanni (1998) posit that programming in these areas is every bit as necessary as academic programming in preparing students with mental illnesses for the transition into the adult world.

Several respondents stated that increased levels of self-awareness and acceptance facilitated a sense of personal empowerment. This coincides with Jones (1996) who states that individuals who accept their illness, and have insight into its impact, develop a sense of personal value empowering them to move forward with their lives. This was articulated by one respondent who stated that her road to recovery began when she made the decision in her Grade 11 year that she was no longer going to work under the pressures inherent in the high

school system. She has never doubted her decision to complete her high school credits first in an alternate school within the public school system and then in an adult setting. She feels she took control of her life and credits both smaller schools with enabling her to finish her high school education, while minimizing the impact of her illness on her daily functioning. As Jones suggests, this respondent felt that her decision to leave public school was the first step in taking control of her life and reuniting with herself.

The experience of this respondent in becoming empowered may juxtapose with another who, at 34 states that he is no closer to accepting his illness than when he was in high school. It has been ten years since he has completed high school and he voices frustration about having to be on medication and about his illness interrupting his work history.

Respondents' ability to accept their illness and put their pasts behind them, largely determined the quality of their current lives. Their stories indicate that their high school experiences were unsuccessful in helping them prepare for the adult world in which they later found themselves. Their personal accounts and the existing literature in the area have implications for the education of students with mental illnesses.

### **Implications**

Entering into the lived world of individuals who were diagnosed with a mental illness during their high school years, provided me with a deeper insight into this lived experience. The respondents used similar images, metaphors, and

analogies to bring their experiences to life. Their shared struggle to find meaning, coupled with their eagerness to share their memories and reflections helped me to translate their lived reality into text.

The text that emerges validates for adolescents and their parents the many challenges and hardships faced by young people with severe psychiatric disorders within the public school system. Such knowledge can help guide these families through the difficult and often lonely process of being their child's sole support. Equally significant is that this study has implications for teacher training and educational practice, policy and research. The study illustrates that additional training is desperately needed and that the fledging knowledge that exists for these children is being ignored.

For adolescents with mental illnesses, this study can assure them that they are not alone; that the challenges and struggles they face have been endured by others. The eagerness with which the respondents shared their stories invites adolescents with mental illnesses to break the silence, to maintain hope, and to know that recovery and success are possible.

For parents of students with diagnosed psychiatric disorders, this study legitimizes their concerns regarding the school system's ability to meet the needs of their children. The study is a reminder to parents that they are the primary support system for their child and, as such, need to advocate on their behalf. Parents' entry into the lived world of the participants in the study, can serve to increase their insight into the challenges experienced by their own children. The

personal accounts of the individuals in the study may help parents realize that even with family love and support, attending high school after the onset of a mental illness is a lonely and frustrating experience.

A significant portion of the school population is affected by mental illness, and teachers encounter these students in their classroom on a regular basis. Individuals with internalizing disorders such as anxiety and depression often go unnoticed and/or untreated. Teachers have the same expectations and the same set of rules for these students. Often, success is measured by and recognition given for the attainment of curriculum outcomes, only. This study indicates that a teaching philosophy focused solely on curriculum outcomes will not meet the needs of high school students with psychiatric disorders.

Educators are reminded of the paramount role they play in developing and implementing programs for students with psychiatric disorders.

Lack of teacher awareness remains a large problem. This study calls on all teachers to take personal initiative in increasing their knowledge in the area. As leaders of our children teachers' professional responsibility extends to promoting both school-wide and community awareness.

Van Manen (2003) states that the true pedagogical nature of teaching demands that we ask what is a situation like for a particular student and what is appropriate for the student in that situation. In defining pedagogy the "theory of the unique," as Van Manen calls it, limits the place of dominant education perspectives, learning theories, and teaching models in determining what is

appropriate for a particular student in a particular situation. An understanding by teachers of how these students experience academic and social demands can alter teacher expectations in a way that will promote learning and reduce student pressure and anxiety.

This study indicates that there is a need for the reexamination of the role of guidance counsellor within the high school setting and/or a reworking of the services that they provide. Individuals in this study perceived the role of the high school guidance counsellor as one of assisting university bound students to make sound curriculum choices to facilitate career planning. They perceived high school guidance counsellors as making themselves visible and available almost exclusively in this capacity. Often, these university bound students are self-motivated and the dissemination of information is largely clerical. Students with mental illnesses go through high school feeling disconnected to the curriculum, the student body, the teachers, and the school space itself. The guidance counsellor could play a vital role in promoting school wide awareness, integrating school-based services, providing holistic counselling and perhaps preventing or limiting the need for alternate school settings for students with mental illnesses.

Policy makers are reminded that educational policy and practice are intended first and foremost to serve the needs of the students. To be effective each must be a reflection of the other. More than any other group, students with EBD, in particular those with severe psychiatric disorders, have unique challenges which call for flexibility in programming, a variety of placement options and an

inherent need to exercise professional judgement in a case-by-case, situation-by-situation, manner. If this is to be accomplished through an integrated team approach, there is a need for policies which are informed by professionals in the field and which reflect proven practices. The literature abounds with evidence that no one educational practice or policy, however soundly grounded in research, can meet the needs of all students. These students tell us the regular classroom is not the environment that will meet their needs. This finding supports researchers such as Allan and Brown (2001) and MacMillan, Gresham, and Forness, (1996) who call for a more individualized approach to planning based on individually defined civil rights.

For researchers, this study raises many questions regarding the education of students with diagnosed psychiatric disorders. What are parents' experiences and perceptions in dealing with the education system? What is teachers' awareness level regarding the identifying characteristics of mental illness, its prevalence in the school system, and proper referral procedures? Given the eagerness and clarity with which these respondents spoke, further phenomenological studies would be a welcomed addition to the limited amount of research in the area. Education policy and practice will continue to lack this relevance unless it is informed by those it seeks to serve.

To this end, it would be appropriate to give the final words on the implications of this study to the respondents themselves. They know better than anyone else, certainly this researcher, the implications of their lived experiences.

Students spoke of the need for increased public and school-wide awareness regarding mental illness. They reflected upon their own lack of knowledge in the area and felt that the medical profession has to do more to help individuals truly understand the nature of their illnesses. They maintained that increased teacher and student awareness would help prevent others from having to, do as they did, return to school guarding a secret.

Respondents named teacher flexibility and additional programming options as vital components of effective service delivery for students with psychiatric disorders. More practical, vocational and insight-oriented programs with less emphasis on a university-bound education were suggested to help alleviate some of the pressure they experienced.

Respondents saw the need for significant changes to the role of the high school guidance counsellor. They suggested that they move away from administrative duties and an emphasis on university planning so that the needs of the entire student population could be viewed holistically. Respondents believed that the guidance counsellor should play a prominent role in promoting school-wide awareness in the area of mental illness. Individuals suggested that if counsellors were more visible in this role, individual and group counselling, both formal and informal, would be a natural outcome.

While respondents felt that the current system needed to change, they were equally clear in saying that separate units or schools would still be necessary. The exact structure of proposed alternate sites varied among



respondents. Some recommended a small unit attached to the school where students with mental illness could receive individualized help or could use as a place of refuge, when unable to cope in the regular classroom. Others were more adamant in stating that an alternate school would be absolutely necessary for individuals with psychiatric disorders. They maintained that the nature of mental illnesses and the constitution of public schools are not compatible. They advocate for additional money and resources to be placed into small separate schools within the public system, as well as adult school settings, to enable individuals with psychiatric disorders to complete their education.

What emerges is a clear call for drastic changes so that students with psychiatric disorders have options for obtaining a high school education in a safe and positive environment. The existing system, even with its well-articulated interagency approach to supporting students with diverse needs, is failing. The policy and practice are as far apart, for these students, as could possible be. While knowledge and services are clearly needed, sensitivity to the needs of students is paramount.

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## Appendix A

### Letter of Introduction For Mental Health Agency

Marie Young  
Masters Candidate  
Faculty of Education  
Memorial University of Newfoundland  
Apt 306, Building 48 Pasadena Crescent  
St. John's, Newfoundland

August 18, 2003

To Whom it May Concern:

I am a Masters student in the Educational Psychology Program of the Faculty of Education at Memorial University of Newfoundland. I am currently conducting a research project under the supervision of Dr. David Philpott as part of the requirements for the degree of Masters of Education. I am writing to provide information regarding my research project: A phenomenological study of students' experiences in returning to school after the onset of a psychiatric illness.

The goal of the study is to try to understand the experiences of students with psychiatric disorders as they attempt to re-integrate into the school system after the onset of a psychiatric disorder. It is hoped that the study will provide a forum for individuals with mental illness to tell their stories. Such first hand accounts of living with a mental illness and attempting to re-integrate into society (in this case return to school) after diagnosis and a break in normal activities can serve to increase awareness and understanding of the unique challenges that these individuals face. The study might also serve to provide validation for individuals and families directly affected by mental illness, as they identify with others who have encountered similar struggles. Finally, it will help education and mental health professionals in their efforts to identify effective supports and to see more clearly if there is a breakdown between policy and practice.

There is a need for increased awareness of the unique challenges of students with psychiatric illnesses. It is anticipated that the findings of this proposed study will add to the limited body of literature on the academic and social experiences of this population. Such data could be used to help educators and mental health professionals provide more effective interventions and education programs for individuals with significant mental health problems.

I am requesting your involvement in my study by asking that you identify potential participants. Participants must be at least 19 years of age and have had their high

school experience interrupted by the onset of a psychiatric disorder, following which they attempted to return to school. Candidates for the study must have exited the secondary school system. However, they may be looking for work, attending community colleges for upgrading, enrolled in alternative schools such as the TI Murphy Center or attending post-secondary institutions.

I also ask that you identify only those individuals, who in your judgement are intellectually and emotionally capable of participating in the study. It would be helpful if you could explain to the potential participants the nature of the study and discuss with them the meaning of informed consent, limits to confidentiality, and any concerns you or your client may have about possible emotional harm or any negative impact an individual might experience from participation in the study.

I request that you be available to discuss with clients the introduction letter, inviting them to participate in the study. This letter outlines how participants' rights will be protected. It also makes clear that this is an independent study and involvement by mental health professionals, in no way indicates their validation or endorsement of the study. The letter of introduction to the participant also states that refusal to participate in the study will not interfere with the relationship between client and mental health professional and information gained through the study will not be communicated back to the mental health agency (unless dictated by legal limits of confidentiality, which will be clearly outlined on participant's letter of introduction).

Participant's involvement in the study will consist of an audio taped interview lasting approximately one hour. I ask that you distribute the appropriate forms to potential candidates, who in turn can contact me by telephone or by returning the consent form to the address provided.

This study has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University of Newfoundland. I thank you in advance for your consideration in identifying potential candidates for this research project. If you have further questions or concerns, please contact me at 738-2150.

Sincerely,

Marie Young

## Appendix B

### Letter of Introduction Research Participant

Marie Young  
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Memorial University of Newfoundland  
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August 18, 2003

To Whom it May Concern:

I am a Masters student in the Educational Psychology Program of the Faculty of Education at Memorial University of Newfoundland. I am currently conducting a research project under the supervision of Dr. David Philpott as part of the requirements for the degree of Masters of Education. I am writing to provide information regarding my research project: A phenomenological study of students' experiences in returning to school after the onset of a psychiatric illness.

The goal of the study is to gain greater understanding of the lived experiences of students with psychiatric disorders as they attempt to re-integrate into the school system after diagnosis of their illness. There is little awareness in the educational field of the unique challenges faced by this population of students. I believe that the information gained from this study will provide important data which can be used to help educators and mental health professionals provide more effective interventions and education programs for students with significant mental health problems.

I invite you to participate in this study and encourage you to discuss participation with a counsellor, family member or other support person before making your decision. I also want to let you know that this is an independent study and is by no means validated or endorsed by the mental health professional who provided you with this letter of information. Your decision to participate or decline participation will in no way interfere with any client/therapist relationship and any information gained through the study will not be communicated with the mental health agencies in which you are involved (unless dictated by legal limits of confidentiality which are outlined below).

Should you choose to participate, I would like to meet and talk with you about your high school experiences. I will arrange a personal interview at your

convenience and at a mutually decided location. I will make every effort to pay attention to your comfort level and convenience during the interview. It is possible that recalling your school related experiences after the onset of your illness will bring forth upsetting memories and feelings. It is important that you know that you have the right to stop the interview at any time and refuse to answer questions or discuss topics with which you are not comfortable.

If you anticipate a strong emotional response to participation in the study you are encouraged to decline this invitation. If during the interview you become visibly upset or disclose such feelings to me, I will assist you in obtaining appropriate professional help, if required. With your permission, I will make contact with you in the days following the interview and you will be free to contact me if I can be of assistance in obtaining help for any emotional upset that you had not anticipated as a result of participation in the study.

The interview will last approximately one hour and will be audio taped and later transcribed. All information will be considered confidential unless one of the following limits of confidentiality apply. I will be legally obligated to disclose to the proper authorities any information regarding abuse or possible abuse of children under the age of 16 and to report intentions of self-harm or harm to others that you disclose. I would also be obligated to respond to a court order by providing requested information. Other than one of the above conditions all information that I receive will be held in strict confidence.

All audio tapes, discs, field notes and transcripts will be kept in a locked cabinet in a locked room in my place of residence. Only I will have access to the information. Transcripts and notes will be numerically coded. The key to the code and the signed consent forms will be held in a locked cabinet in my supervisor's office at Memorial University.

All information will be destroyed at the completion of the project or immediately after your withdrawal should you decide to discontinue. Data will be destroyed in the presence of my university supervisor. Transcribed notes and written information will be shredded via a shredding machine. Discs will be erased and broken. Audio tapes will be burned.

The results of the study will be made available to you upon request.

Thank you for your time in reading the above information. I appreciate any consideration you give to participating in this project. I believe that this study will increase awareness of the unique challenges faced by individuals with psychiatric illnesses as they attempt to move through the school system.

Such data should help improve program planning for this population of students at the secondary school level.

If you have any questions or concerns please feel free to contact me at 738-2150 or my supervisor Dr. David Philpott at 737-3506. This research proposal has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University of Newfoundland and if you have any ethical concerns about the research, you may contact the Chairperson of ICEHR at 737-8368.

If you decide to participate in this study please contact me as soon as possible by calling me at 738-2150 or by returning one of the enclosed consent forms in the self-addressed stamped envelope. I ask that you sign both copies of the consent form provided, keeping one for your records.

Thank you for your co-operation.

Sincerely,

Marie Young

## Appendix C

### Research Participant - Consent Form

My name is Marie Young and I am a Masters student in the Educational Psychology Program of the Faculty of Education at Memorial University. I am currently conducting research on the experiences of adolescents in returning to school after the onset and diagnosis of a psychiatric disorder. I am requesting your consent to participate in this research and would like to meet and talk with you about your experiences.

Your participation will consist of an audio taped personal interview at your convenience and at a mutually decided location. The interview will take approximately one hour. Some follow up by phone may be necessary for clarification purposes.

Information that you provide will be kept confidential (unless dictated by legal limits of confidentiality as outlined in the letter of introduction). You will not be identified or identifiable. Audio tapes, field notes, transcripts and discs will be kept in a locked cabinet in my place of residence and will be destroyed upon completion of the project. Participation in this study is entirely voluntary and you have the right to withdraw from the study at any time. The results of my research will be made available to you upon request.

This research has been approved by Memorial University of Newfoundland's Interdisciplinary Committee on Ethics in Human Research. If you have any ethical concerns you may contact the chairperson of ICEHR at 737-8368. If you have any questions please do not hesitate to contact me, Marie Young, at 738-2150. If you wish to speak to my supervisor you may do so by calling Dr. David Philpott at Memorial University, 737-3506.

Your signature on this form indicates that you have read the letter of introduction and that you understand the purpose of the study, potential harms and benefits, how your rights will be protected, and legal limits to confidentiality, and agree to participate in the study. I ask that you indicate the method by which you wish to be contacted by entering either your mailing address, telephone number, or both in the space provided.

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 Participant's Signature

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 Date

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 Investigator's Signature

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 Date



## **Appendix D**

### **Researcher's Bracketing Experience**

It is as a parent and as a teacher that I reflect on my values, beliefs and assumptions regarding the right of all children to be educated to their full potential. I stayed home with my two children during their pre-school and primary school years. My library visits, kindergym participation, and other early childhood activities were as educational for me as they were for my children. Having a girl and a boy sixteen months apart, I knew I was in for an adventure but I was unaware how remarkable that adventure would be. My children were accommodating enough to confirm some of what I had learned about Piaget's stages of cognitive development. They certainly were not predictable in many other ways. What I guess was most striking was the differences in their interests, personalities, ways of learning, and emotional reactions.

After my children entered elementary school, I returned to university to complete a special education degree. I was hardly surprised to find that there was an emphasis in special education courses on individual differences of students with disabilities. I knew first hand that this was true for my children who, without disabilities, were definitely unique individuals. I was enthusiastic and excited about my university studies. My head was filled with all the latest special education theories, practices and policies. I remembered my own schooling and recognized how far the education system had come in programming for students with learning challenges.



I was idealistic and enthusiastic when I started my teaching career. Now, following years of having worked with students with various types of disabilities, and their families, I find myself battling to hold on to that idealism. However, my enthusiasm for working with students with learning challenges has not waned. As a learning disabilities itinerant teacher, an important part of my job was to advocate for students with diagnosed learning disabilities. Many dedicated and caring teachers went the extra mile to provide needed accommodations for students with reading, writing, and other learning disabilities. I commend those teachers.

However, the teachers who refused to believe in learning disabilities and who refused to make necessary accommodations were of great concern, causing students with learning disabilities considerable harm. Being repeatedly singled out in the area of their weakness is a misfortune many LD students had to bare. My disillusionment came when I realized that the policy in place to protect students with disabilities, including learning disabilities, was only remotely related to actual practices.

When I started working with students with psychiatric disorders, I was not at all surprised to find a break down between policy and practice. I had seen it in other areas and had no reason to expect anything different in the services received by these students. Lack of awareness, lack of resources, and lack of professional training and commitment combined to make educational programming for these students far from adequate. The stories I heard from

students with psychiatric illnesses and their parents inspired me to do this research. There was much to gain and nothing to lose.

As a phenomenological researcher, it was my responsibility to 'bracket' or suspend as much as possible my own beliefs and assumptions with regard to this population of students, when conducting the formal interviews. Although as a participant/observer in the research study, I could not and did not attempt to remove my self completely from the interactive process, I remained aware of my own pre-conceived notions and was vigilant in attending to words and nuances displayed by the research participant. My use of journal writing was one way to separate my perceptions from the respondents and I found myself entering a process of careful reflection and rigorous analysis. My decision to be interviewed by a colleague regarding my experience and opinions in the area of mental illness, also proved to be valuable in the bracketing process, as did the later analysis of the transcribed audio tape.

## **Appendix E**

### **Glossary of Terms**

#### ***Psychiatric Disorder***

The term psychiatric disorder is defined by the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM –1V) as:

A clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (such as painful symptom) or disability (such as impairment in one or more important areas of functioning) or with a significantly increased risk of suffering, death, pain, disability, or an important loss of freedom. (cited in Hales & Hales, p. 34).

For purposes of this study the term 'psychiatric disorder' refers only to disorders that require medical intervention and follow up such as major depression, generalized anxiety, social phobia, schizophrenia, and bipolar disorder. It will exclude disorders associated almost exclusively with childhood and adolescence such as attention deficit with hyperactivity (ADHD), conduct disorder (CD), and oppositional defiant disorder (ODD).

#### ***Emotional Behavioral Disorder (EBD)***

Emotional/behavioral disorder (EBD) is a broad educational term used to categorize students with any of a number of severe behavioral or emotional problems that negatively affect functioning and performance. It includes disorders

characterized by 'acting out' behaviors such as ADHD, CD, and ODD, as well various psychiatric disorders or mental illnesses. It is defined by the Council of Children with Behavioral Disorders (CCBD), as:

A condition in which behavioral or emotional responses of an individual in school are so significantly different in degree and/or kind from his or her generally accepted age appropriate, ethnic or cultural norms that they adversely affect educational performance in one or more areas: self-care, social relationships, personal adjustment, academic progress, classroom behavior or work adjustment (Government of Newfoundland and Labrador, 1996, p. 28).

### ***External Manifestations of EBD***

External manifestations of EBD include overtly disruptive and persistent acts of aggression such as fighting, defiance, and destruction of property; oppositional and non-compliant behaviors; and a persistent pattern of lying, stealing, or cheating (Government of Newfoundland and Labrador, May, 1996).

### ***Internal Manifestations of EBD***

Internal indicators of EBD include depression, fear and anxiety, withdrawal, obsession, self-consciousness, somatic complaints, exaggerated reactions to routine and for this study auditory and visual hallucinations [auditory and visual hallucinations are generally considered external manifestations of EBD] (Government of Newfoundland and Labrador, May, 1996).

***Interagency Collaboration***

Interagency collaboration is a system of care which advocates coordination and integration of services for students with disabilities by the collaboration of all persons and agencies involved including home, school, health, mental health, human resources, social services, and justice (Pumariega & Vance, 1999).

***Case Management***

Case management is the integration of service provision through the assignment of an individual (case manager) to coordinate services and advocate for students and their families linking them to community resources. The case manager plays a critical role in ensuring that treatment plans are developed and necessary interventions are implemented (Shantz, 1994).





