

RECORDING THE PARENT'S VOICE:
LISTENING TO PARENTS OF ADOLESCENTS WITH
EMOTIONAL DISTURBANCE

By

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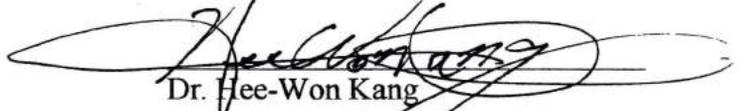
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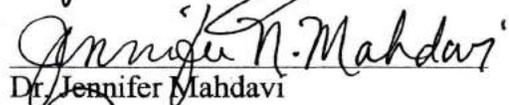
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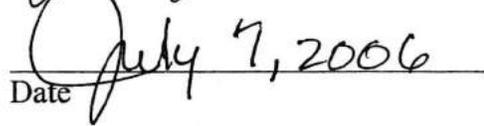
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ABSTRACT

Purpose of the Study:

Research has demonstrated that parents of students with Emotional Disturbance (ED) have not been seen as full partners in the Individualized Education Plan (IEP) process. There have been few studies where parental opinion regarding the IEP for students with ED has been analyzed and discussed. The research of this thesis is to interview and record the thoughts, observations, and ideas of parents of adolescents with ED regarding the Individualized Education Plan process for Special Education and the services received by their adolescents under this plan. The hypothesis is that by recording the parent's voice, this thesis will increase the body of knowledge as to the parent's view regarding the IEP process and collaboration.

Procedure:

In this thesis, parents of adolescents with ED were interviewed regarding their observations and ideas concerning the IEP, including assessment for special education, collaboration between institutions and parents, and the positive and challenging aspects of the process. These data were then coded and analyzed for concurrent themes between interviewees.

Findings:

The parents in this study report that the parent component of collaboration in the IEP process was often overlooked, leaving the parent without a say in the adolescent's educational goals. Parents were found to lack trust in the school system to provide appropriate services to their adolescents with ED because parents felt that the assessments were often inaccurate and the programs offered seemed lacking in effectiveness. Parents thought that they were not educated and informed about the IEP process in such a way that they could then be equal partners with the school in the collaborative process. Parents felt isolated and stressed the importance of having a parent support group or mentor. Parents turned to outside resources to help in the education of their students with ED. Finally, the parents described the importance of the individual teacher, administrator, or psychologist either to help their child receive services or to deny services. Overwhelmingly, with the exception of a few instances in which

adolescents received appropriate services, parents described experiences of the IEP process in negative terms.

Conclusion:

This study investigated the parent's view regarding numerous aspects of educating the child with ED. Although IDEA states the importance of collaboration between school and parent, this study did not find that such collaboration always occurs. This study has found that parents have knowledge and enthusiasm, and can be effective partners, if schools will listen. This study has significance for the general literature in that it supports current research indicating that parents are not part of the process, yet have important information to share.

Chair: _____

Signature

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Chapter 1

Introduction

In the United States, a significant number of students under the age of 18 have mental illness. Mental illness is a common term used within society to describe individuals with considerable impairments such as depression, schizophrenia, or obsessive-compulsive disorder. The ability of adolescents with mental illness to function in a school setting is varied. Emotional disturbance (ED) is the label used by the Individuals with Disabilities Education Act (IDEA) to define whether a child's mental illness is significantly impacting his or her education. This term is only used within the educational setting. Within the laws of the U.S. (Individuals with Disability Education Act and Section 504 of the Rehabilitation Act of 1973), the educational rights of adolescents with disabilities are addressed. Surprisingly, of the 11% of adolescents suffering from mental illness, only .74% of these are identified for the purposes of receiving special services within the schools (IDEA Identification Rates). Only one-third of students with emotional disturbances complete school (Johns, Crowley, & Guetzloe, 2002). All of these problems have implications not only for the adolescents, but also for society at large. As they leave their educational years behind, these students may become adults with poor employment histories and high arrest rates (Mattison & Felix, 1997).

There are many difficulties in accessing special education services for students with ED. First, there is a lack of consensus as to the characteristics that will qualify students for special services because the actual terminology that defines the characteristics of adolescents with emotional disturbance is vague (Center for Effective Collaboration and Practice, 2001). Second, it has been found that within school systems,

the identification process is subjective and slow in identifying students with ED. As a result of the inconsistency of the identification process, many of these students are left unidentified and thus never receive the services that they need (Center for Effective Collaboration and Practice, 2001). Third, when students are identified (either by teachers, administrators, or parents) as possibly requiring special education because of a mental illness, an assessment must then be made to determine the student's eligibility for special education under the purview of the law. The assessment process requires a sufficiently comprehensive evaluation in order that students will receive the appropriate services. This may include an assessment of emotional factors that may not be readily observed (Cal. Ed. Code §56320(f)). Fourth, students assessed with emotional disturbance often do not receive appropriate services either because students with ED require complicated delivery processes that involve numerous agencies or schools lack effective curriculum for students with ED. This is particularly the case in the area of social skills education (Kavale & Forness, 1996).

I think that parental involvement is key to the educational outcome of all adolescents. When parents are involved, students attend school more consistently, demonstrate better behavior, and perform at a higher academic level (Wagner et al., 2005). Schools, however, are slow to include parents. In the general education population, 95% of parents say they have no role in curriculum decisions although 50% of these parents would like such a role (Klein et al., 1980). On the other hand, it has been my experience that PTA meetings and parent education nights in Marin County have consistently low attendance. What are the causes of lack of parental participation?

This question is difficult to answer, especially in the case of parents of adolescents with ED. Often these parents have experienced past challenges with schools and other systems and are reluctant to engage in those systems in ways their adolescents need (Wagner, Kutash, Epstein, & Sumi, 2005). It is important to examine the views of the parent of the child with ED. Parents may have important information that, if shared, might lead to the possible development of remedies to the plethora of issues that presently complicate the education of students with ED.

In this study, I conducted interviews of three mothers of students with ED regarding the IEP process. The parents were familiar with Marin County special education. My desire for this study is that it empower those who participate, inform those who access the information presented, and foster collaboration by giving insight into the parent's world to teachers and administrators.

Goals of Study

Given the challenges of educating students with emotional disturbance and the importance of parental involvement, this study will record the thoughts, observations, and ideas of three parents of adolescents with ED regarding the IEP (including assessment) for special education, collaboration between institutions and parents, and the positive and challenging aspects of developing an appropriate education for students with ED. I hope to add to the body of knowledge about the issues of importance to the parents of students with emotional disturbance and illuminate the validity of the collaborative process.

Chapter 2

Review of the Literature

In order to establish a basis for this study, I have highlighted the emotional disturbance (ED) classification as defined by Individuals with Disabilities Education Act (IDEA). Additionally, I have examined several models of education for students with ED. Educating the child with emotional disturbance is a collaborative effort, and I will discuss the impact of the collaborative model on the Individualized Education Plan (IEP).

Background

Unfortunately, some adolescents suffer from debilitating and stigmatizing mental illness. When mental illness adversely affects an adolescent's educational performance, the adolescent must, by law, receive a free, appropriate, public education (FAPE). Mental illness is characterized by impairments of normal cognitive, emotional, or behavioral functioning. Social functioning is also often impaired. Adolescents with mental illness are likely to have been diagnosed by psychiatrists, psychologists, or other health professionals based on the criteria specified in the *Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV)*. Through out this thesis, I will use the terms *mental illness* and *emotional disturbance (ED)* interchangeably. One is a medical definition, and the other is an educational definition. A *DSM-IV*-based assessment is the standard of psychiatric diagnosis; however, in order for a student with ED to access special education in the public school system, he or she must also meet the following criteria set forth in Individuals with Disabilities Education Act.

Definition

According to the IDEA, the definition of emotional disturbance is as follows:

(i) The term means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance: (A) An inability to learn that cannot be explained by intellectual, sensory, or health factors. (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers. (C) Inappropriate types of behavior or feelings under normal circumstances. (D) A general pervasive mood of unhappiness or depression. (E) A tendency to develop physical symptoms or fears associated with personal or school problems. (ii) The term includes schizophrenia. The term does not apply to adolescents who are socially maladjusted, unless it is determined that they have an emotional disturbance. (Individuals with Disabilities Education Act, 34 C.F.R. §300.7(c)(4)(i)(ii), 2006)

Issues

There is no consensus between states as to the definition of ED. Because states interpret the criteria differently, there is a variation of 33% between states as to the identification of students with ED (Center for Effective Collaboration and Practice, 2001). Numerous court cases as well as operational definitions supplied by the Office of Special Education Programs (OSEP) have involved efforts to clarify the intent of the law. Following are some of the issues with the poorly worded legal definitions.

"Over a long period of time." The criterion "over a long period of time" does not have a quantifiable number of days or months, which leaves the term open for interpretation. OSEP finds that an acceptable definition of "over a long period of time" is from 2 to 9 months. Also, interventions (this term is also not defined) that address the child's emotional disturbance must be in process during the 2 to 9 months for the definition to be fully effective (Gorn, 1999). Clearly, a child may have emotional

disturbance, but not be receiving therapy or other types of interventions, during the 2- to 9-month time period, and thus will not be qualified as having ED.

"Inappropriate types of behavior under normal circumstances." Numerous court cases have attempted to define "inappropriate types of behavior under normal circumstances." In one case, the courts found that a student need not demonstrate bizarre, dangerous, psychotic, or delusional actions in order to exhibit inappropriate behavior (Clint Indep. Sch. Dist., 1986). Another case found that a student was not eligible for special education because it was determined the student's lack of impulse control, poor judgment, and refusal to conform behavior to known requirements was volitional (Stanislaus County Office of Educ., 1985). Again, this is another term that is open to interpretation.

"A general pervasive mood of unhappiness or depression." In California, a court case addressed the issue of whether a child must meet the *DSM-IV* criteria for major depression in order to qualify for services (Conejo Valley Unified Sch. Dist., 1985). The court ruled that a student need not meet this criteria; however, the lack of *DSM-IV* diagnosis can legitimately raise issues about whether or not a student is depressed *enough* to receive services.

"Socially maladjusted." This term has been the subject of much debate. This is not a legal term, nor is it defined by IDEA. Social maladjustment is generally understood as persistent misbehavior that operates outside acceptable norms (Gorn, 1999). Mistakenly, many school psychologists deny services to students because these students display either conduct disorder or some other externalizing, aggressive behavior. To the psychologist, the conditions that are often labeled as conduct disorder, externalizing

aggressive behavior, and social maladjustment are interchangeable, when in fact conduct disorder or externalizing aggressive behavior should not be seen as evidence of social maladjustment.

Adolescents with conduct disorder repeatedly violate the personal or property rights of others and the basic expectations of society. A diagnosis of conduct disorder is likely when symptoms continue for 6 months or longer. Conduct disorder is known as a "disruptive behavior disorder" because of its impact on adolescents and their families, neighbors, and schools. (United States Department of Health and Human Services, 2003)

In a study done by Forness and Cavil (1989), the authors state that "the vast majority of adolescents in their sample who were ultimately placed in Seriously Emotionally Disturbed classes after psychiatric hospitalization had in fact received a diagnosis of conduct disorders [at an earlier date]" (p. 283). Forness and Cavil conclude that conduct disorder should not preclude a child from receiving special education. In addition, social maladjustment has been cross-correlated as "externalizing aggressive behavior." Yet aggressive behavior can be a symptom of childhood depression. Childhood depression is often exhibited through aggression, irritability, and disruptive behavior. Forness and Knitzer (1992) conclude that the IDEA terminology is either vague or inaccurate, and the definitions of the various criteria are not comprehensive.

History

Obviously, the laws and societal expectations for the education of the child with ED are still evolving. It is important to look back in time and recognize how far our society and its concern for those with disabilities have come. Even though a person may have mental retardation and emotional disturbance co-occurring, in earlier times mental retardation and emotional disturbance were not differentiated. Often a person was placed in an institution for mental retardation when he or she had an emotional disturbance. Or,

if they were placed in a school setting, adolescents with ED were placed in special ungraded classes that included adolescents with mental retardation and learning disabilities, and those who could not speak English (Kaufmann & Landrum, 2006). Sadly, this still occurs currently, but not to the same extent as in the past. More often than not, adolescents with disabilities were not allowed to go to school, in part because the child with a disability took up too much teacher time, negatively affected school discipline and progress, could not benefit from instruction, and was disruptive to other students (Yell, 1998).

The history of adolescents with ED is intertwined with the history of adolescents with disabilities. Within the last one hundred years, great strides have been made in educating adolescents with ED. By the 1950s, the education of adolescents with ED became a field of its own. Research began on the importance in educating adolescents with emotional disturbance (Kaufmann & Landrum, 2006). During the 1960s and 1970s, research in the area of adolescents with ED increased. Parental advocacy and the implementation of federal statutes are both important factors in the history of education of students with disabilities. I will discuss each of these factors in more detail.

Parental advocacy. School became compulsory for all adolescents in the United States at the beginning of the twentieth century. 1910 saw the first White House Conference define programs for adolescents with disabilities. As a result of the conference, adolescents with disabilities began to be moved from separate, non-educational warehousing institutions into segregated classes within traditional public schools. Even though it initially seemed like a solution for the education of adolescents with disabilities, as time progressed, the adolescents with disabilities were further

isolated from the mainstream population in classrooms that were as restrictive and custodial as the institutions had been. By the 1930s, parents of adolescents with disabilities began to form advocacy groups in response to increasing exclusion of adolescents with disabilities. The first parent advocacy group consisted of five mothers and was formed in 1933 to protest the exclusion of their adolescents with mental retardation from the regular classroom (Yell, 1998).

Although not an issue of parental advocacy, it is important to note that the decade of the 1930s was also a time of innovation for the treatment of mental illness in adolescents. Child guidance clinics of this era made three major innovations: (a) interdisciplinary collaboration, (b) treatment of any child whose behavior was annoying to parents and teachers, not just the most severe cases, and (c) attention to the effects of interpersonal relationships and adult attitudes on child behavior (Kaufmann & Landrum, 2006).

From the 1930s to the 1950s, parent advocacy groups were community based. But, in the 1950s, parents joined together to form national advocacy groups. Parents are still changing the face of education for children with disabilities. Some current advocacy groups include the Families and Advocates Partnership for Education (FAPE), Matrix, Pacer Center, and Parents Helping Parents. These groups are effective in lobbying for the continuing revision of current laws, as well as utilizing the court system to further define and clarify the intent of the law.

Legal statutes. Two of the most important laws affecting adolescents with disabilities are Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Improvement Act of 2004 (IDEA). Additionally, the state of

California passed AB3632 to ensure effective implementation of portions of IDEA. Section 504 of the Rehabilitation Act of 1973 prohibits agencies, including schools, that receive money from the federal government to discriminate against a person with a handicap. As defined by this statute, a "handicapped" person is one who has a physical or mental impairment that substantially limits one or more of the person's major life activities. By law, a student with a disability cannot be denied access to the public school system. Under Section 504, schools are required to provide accommodations so that students may access education.

The Education for All Handicapped Children Act of 1975 (PL 94-142), a landmark case in the evolution for education of students with disabilities, allows a state to choose whether it wants to participate in providing students with disabilities a free, appropriate public education. If the state chooses to participate, then that state receives federal money (Education for All Handicapped Children Act of 1975).

With this law came specific legal mandates for Individualized Education Plans (IEPs) for students. An IEP is a written plan that is implemented in the education of the child with a disability. It must include statements as to the pupil's present levels of academic achievement and functional performance, measurable academic and functional goals, a measure of the progress of the pupil to meet these goals, special education and related services that will be provided to the pupil, an explanation of the extent to which the pupil will not participate with non-disabled students, a statement of accommodations that are necessary to measure academic achievement, the date, location, and duration of services, and transition services beginning at age 16 (Cal. Ed. Code §56345, 2005). PL

94-142 also dictates greater inclusion of students with disabilities into the general student body and that students be educated with their peers to the greatest extent possible.

In 1990, this act was renamed the Individuals with Disabilities Education Act (IDEA). This renaming was an attempt to emphasize the importance of the individual whereas the previous title emphasized the handicap. Other changes to the law were that students with autism and traumatic brain injury were given a separate classification and transition plans were required for students turning 16 years old. This act continues to be amended to help in the education of the child with disabilities. In 1997, the law was reauthorized and significant amendments were made to help improve student performance in school, including strengthening of the role of parents (Individuals with Disabilities Education Act Amendments of 1997). Parents of students with ED must be full partners in the IEP process. This law was again reauthorized in 2004. This current revision grants greater leeway for the school districts in disciplinary procedures, as well as requiring academic assessments as benchmarks for student progress. The therapeutic needs of students with ED can become primary at times, yet the law states the academic needs must still be addressed. The continued amendments to IDEA have positive impact on the student with ED. For example, research has shown that students with ED, once they leave the high school years behind, have poor employment histories and high arrest rates (Mattison & Felix, 1997). The transition plan from school to the adult world can assist the student in making this transition in a positive manner.

In order to assure full implementation of IDEA, California passed Assembly Bill 3632. AB3632 requires that local education agencies (LEA) arrange with other specified agencies to provide related services (needed for students to benefit from special

education) using an interagency agreement. County mental health services through AB3632 are an entitlement and adolescents can receive these services irrespective of their parents' income levels. This law ensures collaboration between the school and county mental health services.

Even though these laws are in effect, I feel that parents are not made aware of their adolescents' rights to appropriate services. I don't think parents know that the school system must provide services to a child with mental illness if the child's education is being impacted. I also think that school systems do not identify or assess adolescents with ED for services to the extent they should. These laws protect the rights of adolescents with ED, but first the parents must be made aware of the mandates, so that the parent can request appropriate services for their children.

Special education is a relatively new field of education and is continually evolving due to the advocacy of parents, teachers, school systems, and lawmakers to make education accessible to all students. And as a result, within the last 30 or so years, the student with emotional disturbance has been given a legal guarantee of public education.

Programs for the Child with ED

Educating adolescents with ED is especially problematic for special education departments in public schools. This is due largely to the wide range of types of mental illness that students with ED can exhibit, such as schizophrenia, depression, obsessive-compulsive disorder, school phobia, generalized anxiety disorder, oppositional-defiant disorder, and suicidal ideation, to name a few. For example, some students with ED may exhibit aggressive behavior towards their peers while others may be reticent to speak

with their peers. Additionally, this variability makes it virtually impossible that any one form of curriculum could hope to address the needs of all these students. An Individualized Education Plan (IEP) is necessary for each of these adolescents, so that their cognitive, social, and emotional needs can be addressed. Most often, the student will not only need academic intervention, but also emotional and behavioral intervention. Research has found that positive focus on student's behavior is the most effective means of engaging students in the learning process (Johns et al., 2002). Given that students with ED have such a large range of needs, there has been much research into types of curriculum that might be effective. I will review a few of the many curricula/programs that are available to students with ED. Some of these models are positive behavioral intervention, positive peer model, wraparound services, and social skills training. All of these models are non-punitive and each focuses on an intervention via curriculum that is based in building upon the positive strengths of each student.

Positive Behavioral Intervention and Support

B. F. Skinner believed that all behavior was modifiable either by positive or negative consequence and postulated that students with behavior disorders engage in inappropriate behavior in order to gain access to reinforcing stimuli (Skinner et al., 2002). In order for these students to engage in appropriate behavior, they must be rewarded for positive behavior. This behavioral model of education is the teaching style utilized in American classrooms. In 1997, the IDEA was amended to include positive behavioral assessment and support as the recommended method of intervention for adolescents in special education (OSEP Technical Assistance Center, n.d.b).

The intent of Positive Behavioral Support is that attention is focused on making the student's problem behavior less effective, efficient, and relevant, and his or her desired behavior more functional. Positive Behavioral Support is comprised of first understanding the function of a challenging behavior and then of creating positive interventions with outcome-based goals that address the underlying purpose of the overt behavior. These interventions are designed to reduce occurrences of the inappropriate behavior and teach new skills to students. Positive Behavioral Support and Interventions are noted for long-term results that reduce inappropriate behavior and also teach appropriate behavior within a variety of settings (Peck, 2004). Positive Behavioral Support needs to be included in all aspects of a child's environment, school, and home in order to be most effective. Parents and teachers must work together to provide consistent, positive behavioral intervention. Through this method, students receive support in maintaining the positive changes in the affected behavior in question (OSEP Technical Assistance Center, n.d.a).

Positive Peer Model

The Positive Peer Model is a program that utilizes the strength of peer support to transform a child into a productive member of their peer group and thus of society. It is well known that adolescent students are highly motivated and influenced by their peers (Cushman, 2006). The use of peer modeling and monitoring can increase social and academic achievement (Heward, 2006).

The Positive Peer Model is based in the constructivist philosophy of education, in which students take responsibility for their own behavior and actions. A trained educator assists in assembling a group of adolescents and monitoring the students' interactions for

appropriate group dynamics. The group establishes norms that influence and shape individual group member behavior. The group dynamic is such that each student impacts the other students through modeling, monitoring, working with buddies, negotiating, and problem solving. Group members can confront other members as to helping vs. hurting behavior towards others. Additionally, group members reinforce the behaviors of individuals who do well. The group also analyzes individual problems, helping to identify strengths so that the individual can build on them. The Positive Peer Model group relies on a variety of approaches, such as cognitive-behavioral, strengths-based, solution-focused, anger management education, self-esteem enhancement, and social skills training. A Positive Peer Model is one in which the students monitor each other. They do this both therapeutically and academically.

Social Skills Curriculum

In order to function with ease in social, academic, or work settings, students must develop necessary social skills. A Social Skills Curriculum is meant to help a student achieve a level of social competence at which he or she can interact with others in an appropriate manner. Adequate social development is the foundation of personal and social adjustment in life. Deficits in social skills lead to limited opportunities for learning and often result in negative academic consequences. With limited social skill, a student's self-esteem suffers and eventually students can begin to feel socially isolated. More specifically, adolescents with ED often either become socially isolated by their peers as a result of the nature of their own actions, or sadder yet, adolescents with ED subject themselves to self-imposed isolation (Johns et al., 2002 p. 80).

A Social Skills Curriculum allows students to gain reinforcement and acceptance for positive patterns of behavior and assistance in learning to avoid aversive situations. Social skills training should not be restricted to teaching specific social skills but used to promote overall social functioning. There are numerous ways to teach social skills, including direct instruction, teachable moment, teacher as role model, recognition of appropriate social skills, special group projects, conflict resolution, and teaching self-management (Johns et al., 2002). Early intervention is most effective in addressing this need. This type of curriculum best takes place in naturalistic settings that include informal procedures that take advantage of incidental learning opportunities. When Social Skills Curriculum is incorporated into the general education classroom, it needs to span more than one year to be most effective. The Social Skills Curriculum is most effective in the general education classroom where students with ED, those at risk, and those students who fall into neither category are taught these skills. (McConaughy et al., 1999).

Wraparound Services

Wraparound Services are a holistic approach in which an attempt is made to meet all of the child's requirements and needs. These services involve intra-organizational, inter-agency, and inter-professional agreements in doing whatever it takes to foster a nurturing environment for students with ED. Organizations such as social services, mental health, welfare, and schools reach agreements to collaborate and form a unified whole in order to support the student and his or her family in a comprehensive manner. In-school programs are linked to out-of-school programs. Mental health services are available in the school, so that there is improved coordination of services to the child

(School-Based Mental Health Services, 2004). Some of the Wraparound Services system elements that promote success are: services that address the needs of the entire family, services that are flexible and provide additional supports not typically found in service provision, provision for family empowerment, learning and skill building, and non-traditional supports (such as family nutritional counseling) (Worthington et al., 2001). The philosophy of Wraparound Services recognizes that the success of the student depends not only upon the student, but also on teachers, social workers, school counselors, nurses, local service providers, community members, parents, and families.

Wraparound Services, in an effort to effect change in all areas of a student's life, also attend to the needs of families through financial, educational, and emotional support. For example, a family without monetary resources might receive rent money, a exhausted family might receive respite care, a family with mental health needs might receive family mental health services (Lazear et al., 1997). Wraparound Services recognize that if the family does not have enough food to eat, this will have an impact on the mental health of the student and thus on the student's ability to learn. Wraparound Services are utilized to assist in maintaining the child in the community in the least restrictive environment.

These are just a few of the many different interventions that can help a child with ED. These are only some of the strategies that could be implemented to help intervene in the complex issue of educating a child with ED. Typically, a child will access numerous supportive interventions that work in conjunction with one another to address the child's needs. Positive Behavioral Intervention and Support, Positive Peer Model, Social Skills Curriculum, as well as Wraparound Services are based on working with the positive aspects of the child. The curricula and interventions are strength based and recognize

that in order for a child to learn, the child must be able to function socially, emotionally, and cognitively.

Parental Involvement

Philosophy

Given that there are so many curricula, programs, teachers, and therapists who care to help and educate the child with ED, why is collaboration with the parent necessary? If one views the education of a child with ED from a philosophical standpoint, there is much to support the necessity of parental interaction. The philosophical theories of pragmatists, progressivists, constructivists, and social constructivists value collaboration. Pragmatists believe in problem solving through group discussions to enhance educational understanding. After the problem has been solved, pragmatists believe that it is necessary to revisit the consequences of actions taken by the group (Ornstein & Hunkins, 1988).

The philosophy of progressivism is based in pragmatism. Progressivism is a philosophy that holds cooperation, choice, and collaboration as some of its essential tenets. Progressivists also believe that education should prepare the student to live in a democratic society by teaching cooperative behaviors and self-discipline. Based in progressivism are the philosophies of constructivism and social constructivism.

Constructivists believe in a curriculum that is customized for the individual student based on the student's prior knowledge and social-constructivism is a philosophy in which understanding is jointly constructed (Berk, 2005). Based in social-constructivism is the practice of collaboration, defined as working together for a common goal.

Each theory contributes to the collaborative model of determining educational outcomes for a child. Constructivists such as John Dewey and Lev Vygotsky believed in collaboration as a method of learning and responsibility sharing. Constructivists believe that parents and educators should work together to construct a curriculum based on a child's needs. Social-constructivists believe that as knowledge and strategies are generated from working together, the group can then collectively work together to help a child become a competent and contributing member of his or her community (Berk, 2005).

Individuals that practice collaboration believe that when parents and teachers, as equals, share in determining the appropriate goals for a child with ED, the child is more likely to have his or her needs (social, cognitive, and behavioral) met. Collaboration is worthwhile work even though it is not easy work. Collaboration requires that professional educators and mental health workers individualize the process for each family, so as to have a successful outcome (Rast, 1997). There needs to be collaboration within and between agencies and parents. When the family is included in the efforts expended by agencies and schools, a circle is created where changes in the child's behavior coincide with changes in the parents' behavior, which in turn leads to changes in family functioning and causes further changes in behavior (Florida Mental Health Institute, 1996). In addition, parents learn appropriate skills and techniques that are utilized in the classroom, so that they can implement these same interventions in the home environment (Florida Mental Health Institute, 1996). Through collaboration and cooperation, parents become more involved and supportive of the academic and

behavioral goals for the child. Collaboration increases the possibility for cohesive and seamless instruction for the child with ED.

Importance of Parent Involvement in the IEP

Parents must be equal partners in the education of their adolescents. The first step in this process is that parents need to be informed of their rights in order to collaborate effectively. Often parents do not understand that they are partners in the educational outcomes of the Individualized Education Plan (IEP) for their child (Individuals with Disabilities Education Act Part B., 2004). The second step is that the collaborative process must value everyone's expertise. Programs that treat parents and teachers as equal partners are more likely to produce outcomes that are valued and supported by both the families and the professionals involved (McConaughy et al., 1999). Parents want to work with professionals who recognize the parents' expertise and knowledge regarding their own adolescents (Johns et al., 2002). If one side, such as the school, holds all the decision-making abilities, the parent becomes disenfranchised.

Parent Involvement in the IEP for Adolescents with ED

I believe that it is imperative that parents be involved in all aspects of the IEP process, from the initial identification and assessment of the child to the development of the IEP and the services offered. However, many parents of adolescents with ED do not participate in the IEP process. One of the reasons for the lack of participation is that the parents are viewed as a problem to be overcome rather than as possible allies to help the child with ED. "Historically, families and caregivers have been treated as the primary cause of adolescent's psychopathology by human service professionals" (Measelle et al., 1998, p. 452). Following from the premise that parents are the cause of a student's

emotional disturbance, programs focus on re-mediating parental deficiencies (Kaufmann & Landrum, 2006). As a result, families are often skeptical of service providers and inclined to under-utilize if not reject social services altogether (Measelle et al., 1998).

Identification. The disenfranchisement of the parent continues in the identification process. In the identification process, a teacher, parent, or administrator may identify a child for assessment for an IEP. School districts are required to find adolescents with special needs in their population. Adolescents with ED are often under-identified and the reasons for this are many. Forness & Cavil (1989) claim:

Under-identification may be due, in part, to lack of effective parental empowerment, shortage of personnel in this particular category of special ed, reluctance of school administrators to identify and serve such adolescents, or a variety of other factors. (p. 282)

However, under-identification is not only due to educational agencies' possible unwillingness to identify these adolescents, but also to parental unwillingness in identifying their adolescents as emotionally disturbed. Parents are constrained and concerned about the pejorative label "student with ED" (Center for Effective Collaboration and Practice, 2001).

Assessment. If a child is identified as having a possible ED that affects his or her ability to access education, the child will then be assessed to see if he or she is eligible for special education services. An important feature of the assessment process is the inclusion of parent information. Yell (1998) writes, "The evaluation will be tailored to assess the child's specific area of educational need, including information provided by the parent that may assist in determining disability and the content of the IEP" (p. 78). Too often, information given by the parent is not deemed to have as much validity as an assessment done by a school psychologist. Interviews with the child, parents, or other

family members remain one of the most important sources of information to help professionals arrive at a diagnosis (Gorn, 1999).

Services. If the school psychologist determines that the child qualifies for the classification of ED, the child then will receive services from the school district. I feel that in the broad context, every IEP for the child with ED should address the emotional and educational needs of the child, but in the narrower context each IEP will vary in how the needs of the student are addressed. Parents need to be partners in determining the IEP goals, and if necessary, the behavioral support plan. Parents can be a resource to help monitor the effectiveness of this process. With ongoing communication between parent and teacher, many of the child's needs are likely to be met.

The California Education Code, as well as the Individuals with Disabilities Education Act, require that one or both of the pupil's parents be represented at the IEP and be allowed the rights of full participation (Cal. Ed. Code §56341(b)(1), 2005). David Cheney (Cheney, Osher, & Caesar, 2002) found that family support and advocacy strengthened student gains in academics. Inclusion of parents is most satisfactory when the parents' opinions are valued. I think that one of the first questions that needs to be asked prior to the IEP meeting is, "What types of services does the family value?" Parents' priorities for the necessary goals for their child may be different than the school psychologist's or teacher's, but they need to be addressed. There has been some research done in determining the types of services parents feel are needed. Lazear et al. (1997) found that families identified continued counseling/therapy, financial aid, and job training as key to success. Interestingly, Worthington et al. (2001) found that clinical services were mentioned less frequently by parents as contributing to successful outcomes. This

study found that within the families researched, the definition of success contained the following elements: basic needs and other goals were met, the child experienced individual achievements, indicators of school success were present, the child's self-esteem and interpersonal relationships with adults, particularly authority figures, improved, the child began to fit in with other adolescents, and the family gained the ability to solve problems independently. From these two studies, it can be seen that the child and the family are an integral unit. The success of the family impacts the success of the child.

To meet the needs of a student with ED, the needs of the parents must be addressed. Parents of adolescents with ED can feel guilty, grief ridden, and exhausted. When the parent is supported, the parent can then support the child. Increased supports are, therefore, warranted for parents of adolescent students with emotional disturbance (Cheney et al., 2002). Schools can partner with social service agencies so that the parents can be provided with crisis assistance, information, and respite care (Johns et al., 2002).

As a child reaches high school, family involvement typically tends to decrease (Cheney et al., 2002). However, there are many ways to foster parental involvement. For example, including parents in staff development activities fosters collaboration, and increases parental knowledge about the factors involved in educating the child with ED. Another technique is to provide ongoing skill development for parents and staff in order to decrease isolation of all involved, and give parents and staff the same tools to support students with challenging behaviors (Cheney et al., 2002). In addition, parents should be allowed to be involved in the day-to-day functioning of a school so that they can serve as models for students as to the importance and validity of education.

Chapter 3

Marin County Programs

This study is based in Marin County, California. In order to fully explain the system of special education in this particular county, I have provided information on the functioning of special education as it relates to adolescents with ED.

Tamalpais Union High School District

Marin County has numerous high school districts. One of these is the Tamalpais Union High School District (TUHSD). There are three traditional high schools in the TUHSD: Redwood, Tamalpais, and Drake. There is also one continuation school, San Andreas, and one independent learning alternative high school. K. Mates, director of special education for the Tamalpais Union High School District, shared the following facts regarding district functioning (personal communication, March 14, 2006).

TUHSD contracts with Full Circle (mostly mental health issues) and New Perspectives (Dual Diagnosis--drugs/alcohol and mental illness) to provide therapeutic support for all of its students, including those in special education. These agencies run group meetings that address such issues as anger management and divorce. Students with ED may access these group meetings.

Each student who has been identified with ED has an IEP. Some of these students also have a behavior plan that is written by the school psychologist. Students with ED may be referred to Marin County Mental Health (MCMH). Referrals are made on an individual basis depending on the needs of the child. Marin County Mental Health provides therapists in the blended classes (whether or not a student has AB 3632 funding)

or on an outpatient basis. An adolescent with ED will be placed in a resource class or a special day class; however, this is a very fluid situation depending upon the child's needs.

Resource Class

This is a class of from one to two periods per day. The student is assisted with organizational skills and class assignments. Resource class can also be utilized as an environment in which the student can take a respite from the general education classes. Resource classes are the same at all of the high schools in the district. Two of the resource teachers at Drake High utilize appropriate sections of the Advancement Via Individual Determination (AVID) model. AVID is a college preparatory program for students who have often been overlooked, and was designed to increase students' opportunities to enroll in four-year colleges. The philosophy is that with support and hard work, adolescents will achieve academically. The teacher helps to develop the academic as well as interpersonal skills to achieve. The basis for this program is writing, inquiry, and collaboration (Swanson, 2000).

Special Day Class

A special day class serves students with similar and more extensive needs. Students may only be enrolled in these classes when the nature of the disability is such that education in the regular class cannot be achieved satisfactorily (Cal. Ed. Code §56364.2). There are two classes that are run in conjunction with MCMH. One class is at the Redwood High School campus and the other is at the Tamalpais High School campus. In each of these classes there is a full-time therapist (MCMH), a special ed teacher, a behavior specialist, and two aides. The two classes are different in that each teacher

brings her own style to the functioning of the program. Group meetings, which might include social skills instruction, are part of the special day class curriculum.

Tamalpais High Special Day Class utilizes a lower level curriculum and deals more with acting-out behaviors. Some of the students in this class have vocational goals as part of their IEPs.

Redwood High Special Day Class uses district curriculum at a slower pace. The students in this class tend to have depression and anxiety. They also have a "Return from Residential" group that meets here. This group is specifically for adolescents who have been in residential treatment for mental illness but are returning to the community.

Marin County Office of Education

When the nature and severity of the ED is such that a student is not able to be educated in the high school district, he or she might need to utilize the services of the Marin County Office of Education (MCOE) program. School districts will contract with MCOE if a child needs a higher level of support than the school district can provide. One example of this could be a child who is "school phobic" and needs more support on a daily basis. T. Sullivan, program manager for MCOE, provided the following data (personal communication, March 14, 2006).

MCOE in partnership with MCMH oversees the Braun Day Treatment Program. The program is administered by Sunny Hills, a private contractor. There are two classes in this program. Each class has a special education teacher and aide. A full-time director who is a marriage and family therapist (M.F.T.), two full time therapists (one M.F.T. and one intern), and two part-time therapists (one M.F.T. and one intern) staff the therapeutic component. Additionally, there are two behavioral counselors. A five-week summer

school program is offered. Each student receives individual therapy once per week, family therapy once per week (often outside of school hours to accommodate parents' work schedules), and group and or social skills education 15 hours per week. Included in the group's activities are art and music therapy, dance, yoga, and drama. A psychiatrist oversees management of medication.

The parents and teachers have ongoing contact. The parents must meet with the teachers for quarterly progress conferences. Students who have most benefited from the MCOE program have done so because of the complete involvement of the family in teaming with the different agencies providing support. The MCOE representative and MCMH representative meet once a week to discuss students. The MCMH representative meets with the therapist (contracted through Sunny Hills) four times per week. Positive behavioral intervention is used as well as a level system. This is a construct in which a student achieves higher levels of independence and responsibility based on achieving certain goals within a level. The curriculum is often project-based learning. A Positive Peer Model is not used, but most activities are group based. Students do have community service projects.

Wraparound Services, utilizing multiple government agencies, are only for the child or family in extreme crisis and at risk of being placed outside of the home at Sunny Hills or other alternate residential treatment programs. If a student should become too aggressive in the classroom, the sheriff is called.

Non-public Schools

When a student has severe behavior issues, such as conduct disorder, the student might be placed at one of the two non-public schools for adolescents with emotional

disturbance in Marin County. These schools more often use a behavioral rather than cognitive/therapeutic model of interventions. Students may be placed there residentially or may be day students. These schools are Sunny Hills and Timothy Murphy.

Timothy Murphy addresses the students in Marin with serious academic, emotional, and behavioral challenges. The school is for boys ages 7 to 18 only. Most students are residents of the residential program on site. Four goals are incorporated into the curriculum: first, an academic goal utilizing an individual educational program; second, a behavioral goal to provide behavioral and therapeutic interventions; third, a community/life skills goal to be achieved through social interaction; and fourth, a learning environment goal that is to provide a safe, nurturing, and structured environment with emphasis on success.

At Sunny Hills, most students are in the residential program. Most of the students have failed in other placements. They serve students ages 5 to 18 who are mentally disturbed, neglected, and abused. The goal here is to address the emotional needs of the students, so that they will be able to access an educational curriculum. This is a treatment program where students receive personalized mental health treatment as well as an individualized education plans.

Chapter 4

Methodology

In order to understand the point of view of parents of adolescents with ED, I set up a study that required that I interview the parents. I then took this data and analyzed it to make determinations of themes and patterns. As I read and coded the data, I kept note of interpretive validity and external validity. By the use of the interview process, I was able to access information that was detailed and true to each family's experiences.

Participants

Three mothers of adolescents with emotional disturbance participated in this study. At the time of the interviews, one woman was married and a stay-at-home mother. She had just undergone major surgery, seemed to have an infection, and had a pump to drain excess fluids from her body, yet she very much wanted to participate and tell her story. Her son has a 504 (this is a section of the Rehabilitation Act of 1973, which requires a school district to provide a free appropriate public education to an individual with a disability) and is attending public high school. Despite the fact that her son did not qualify for an IEP, the information gathered from this mother is still important in that she represents the viewpoint of parents who do not feel that their student is receiving the appropriate educational services, because of the assessment process. The mother did not feel that there was collaboration between school and parent in the identification and assessment process. She states, "...it took threatening legal action till they finally did the testing and then came up with the 504 because they felt that the difference between, I guess, his intelligence, I forgot what the specifics were, were too small. Meanwhile, the kid's very depressed, has had some bad problems in school, and parents are seen as, kind

of, you know, busy bodies if they want to get their kids help." This supports research that found many students with ED are not identified because the assessment for ED is problematic, which results in students with ED who may not be receiving special education services (Landrum & Singh, 1995). This mother's views are important for they offer information about the population of students with ED, who because of the assessment process are denied services. The other two women were divorced and working outside of the home. One had a child with an IEP for emotional disturbance who attends a residential treatment center in another state. The other parent's student is an adult now but had an IEP for emotional disturbance and received Wraparound Services through the county mental health department. The mothers all appeared to be of middle socio-economic status for Marin County.

Data Collection

To collect data, I conducted separate interviews with each of the participants. I used a phenomenological qualitative research approach. "Phenomenology refers to the description of one or more individuals' consciousness and experience of a phenomenon" (Burke & Christensen, 2004, p. 364). I also based the ideological foundation for the interviews in the social-constructivist viewpoint. By interviewing three people, my goal was to construct a view of the IEP process (commencing with identification to services offered) from multiple viewpoints.

Because of confidentiality issues, agencies were unable to give me names of parents of adolescents with ED. Because of this fact, I distributed flyers to Matrix, Parent to Parent (P2P), Sunny Hills, and Marin County Office of Education (MCOE). One parent contacted me through the flyer placed at Matrix, and one through the flyer placed

at P2P. The final parent had heard of my study and had previously expressed an interest in participating.

I conducted the interviews in my place of employment in Larkspur, CA. I work for Virginia Reiss, Licensed Educational Psychologist. I met with each parent individually in the room reserved for client meetings and therapeutic appointments. Each of the subjects sat on the couch and I sat in a chair across from her. I took notes as well as used a tape recorder to capture the data. Each interview took one to two hours. I recorded the interviews as well as took notes. I used an interview guide (Appendix C), but did not adhere strictly to the questions. The interview was a combination of structured and unstructured interview format. I was a full participant in the interview process. The interviews took place during the month of March 2006.

Data Analysis

As Burke Johnson and Larry Christensen (2004) state:

Data analysis requires the reduction and interpretation of the voluminous amount of information collected. Analysis of this volume of data requires reduction to certain patterns, categories, or themes . . . and searching for relationships and patterns until a holistic picture can emerge. (p. 85)

Data analysis requires that I take the raw, transcribed, generalized information and through the use of analyzing and coding, form a discussion.

Each interview was transcribed from the tape recording and then analyzed via coding in the search for pattern matching. "Codes are tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study" (Miles & Huberman, 1994, p. 56). By the use of codes, I was able to reread and sort through material to identify similar phrases, and to isolate patterns and commonalities for further discussion. This is an inductive coding technique, in which transcribed data are reviewed

line by line, and whereby categories are subsequently generated. Categories are then reviewed and refined into slightly more abstract subcategories by careful analysis (Miles & Huberman, 1994, p. 58).

As I carefully read each interview, patterns began to emerge. By using different colored highlighters that correlated to the different theme/patterns, I was able to identify similar phrases within a theme. Besides the use of highlighter, I also used pattern codes, which are brief written descriptors, to further refine the data analysis into more finite subcategories. Pattern codes offer an explanatory and inferential method of identifying data. The large themes were color coded, and the subcategories were pattern coded. I then made an outline, in which each relevant phrase was subcategorized under the major theme.

An example of my coding techniques follows: I reviewed each transcript and found that all of the interviewees cited a lack of knowledge and familiarity with all facets of the IEP. I determined a major theme to be "Lack of Knowledge." I then went through each transcript and highlighted phrases that are applicable to this theme with a yellow highlighter. Going through the yellow-highlighted phrases, I then used pattern codes to refine the subcategories. A subcategory under "Lack of Knowledge" is "Need to Understand the Big Picture (BIGPIC)." The following two phrases were placed in that subcategory, "I had no idea about how IEPs worked" and "I think parents need a broader understanding of what an IEP is." Some phrases were applicable to more than one theme, e.g., "I had no idea about how IEPs worked" was also placed under the major theme "Lack of Trust in Process" and also under the subcategory of "Communication" (COMM).

Interpretive Validity

I took an introduction to counseling class through the Department of Psychology at Sonoma State University. With the insight skills that I learned in this class, I was able to listen carefully to the parents of the adolescents with ED so as to understand their complicated circumstances in greater depth. I had concern and empathy for the participant's perspective. After taking this class, I feel that my skills in accurately portraying the parent's viewpoint, thoughts, feelings, intentions, and experiences were enhanced. With this foundation, I have attempted to interpret the meaning of the parent's statements with accuracy.

Researcher bias/reflexivity. Because I work for Virginia Reiss, I see clients in our office who have become wary of the intent of the school district for effective parent/teacher/administrator collaboration. My bias is to view the school district as not being willing to engage in the collaborative process with the parents. My bias is to think that parents are frustrated and do not feel included in the IEP process. In order to address my own bias, it was necessary for me to have my list of questions reviewed by my thesis advisor. I initially had researcher bias in my interview guide. So, before beginning the process, the questions were modified to affect a more neutral position. After much discussion with my thesis advisor, I felt that I was able to present myself as a disinterested party who did not search for the negative aspects of the IEP in the interview (see Appendix C). In fact, some of my questions were specific as to what were the positive aspects in the education of the child with ED.

Low inference descriptors. In the results section, I included direct quotes from parents. “Verbatims (i.e., direct quotations) are a commonly used type of low-inference descriptors” (Johnson & Christensen, 2004, p. 250).

External Validity

Transferability. The question here is whether the conclusions of the study can be transferred to other contexts (Miles & Huberman, 1994). According to Guba (as cited in Mills, 2003), transferability necessitates including and developing descriptive data and context-relevant statements that permit comparison of the parents I interviewed with other parents. In this study, the statements of the parents are relayed in detail and with accuracy. In addition, I feel that the conclusions are accurate and grounded in the parents’ language and concepts.

Chapter 5

Results

Background

In order to better understand the results of the interview, I believe it is necessary to understand the story of the three parents interviewed. The three mothers self selected to participate in this research project. They are members of advocacy groups and so may have a bias toward expressing negative concerns about the IEP process, however I believe that their views and opinions are reflective of an important group of parents of students with ED. All names in this study are pseudonyms. This information was collected during the interviews.

Alice

Alice has two sons. Her older son, who has ADHD, had an IEP that addressed his needs and her younger son currently has a 504 for emotional disturbance. We discussed her younger son, who is a freshman in high school and failing his classes. Her son has accommodations from the 504, however the general education teachers do not implement these accommodations. Her son does not have a special education teacher, and so Alice is left on her own trying to communicate her son's needs with the general education teachers. She would like an IEP for her son, who is diagnosed schizoaffective and depressed, yet she was denied services. She is at a loss as to what to do. Her son is currently failing high school.

Beth

Beth's daughter is now 27. Her daughter tried to commit suicide when she was 12, and was immediately given an IEP for emotional disturbance. She was placed in

classrooms for LD adolescents and given therapeutic counseling by an intern M.F.T. Beth lost faith in public schools and put her daughter in a private school for two years. Her daughter returned to public school and was not reassessed for an IEP. The daughter was placed in multiple school settings, most often for adjudicated youth. The girl never received educational help again, dropped out of school, and later obtained her GED. She did receive services through county mental health. She is currently diagnosed bi-polar and is on medication.

Carey

Carey's son was kicked out of multiple pre-schools and she was not informed of educational services for preschool adolescents. Carey contacted the school when her son was in first grade to try and implement services for her son, in order to help him behaviorally and socially. The school district gave him speech therapy. By the time he reached middle school, he had an IEP for psychosocial accommodations. He was placed in a non-public school for his freshman year of high school. The mother persisted in finding the appropriate accommodations, and at age 16 he met the criteria for ED. In his junior year of high school, he was placed in a residential treatment center. He will be returning to public school to finish his senior year of high school.

Patterns and Themes

In this section, I discuss the patterns and themes that emerged through the interview analysis and coding. The major themes are: Lack of Knowledge of the Process, Lack of Trust in Process, Lack of Collaboration, Use of Outside Resources, Parental Feelings, and Importance of the Individual. It is important to note that there was a dearth of positive feedback about the IEP process as a whole. Yet, parents did relate some

positive aspects surrounding the education of a child with ED, which will be addressed at the end of this section.

Following is a matrix of the major themes and sub-themes and how often they occurred in the transcripts. These categories are not discrete and there is cross-correlation and overlapping between the categories. It can be seen that parents expressed a lack of trust in the process and lack of collaboration, with high levels of parent feelings about these topics. Even though lack of knowledge, use of outside resources, and the importance of the individual were not mentioned as often, this belies the fact that the statements made within these themes were some of the most powerful and profound.

Table 1

Major Themes and Sub-themes

Major Themes	Sub-themes
Lack of Knowledge (n=19)	Need to understand the "Big Picture"
	Importance of understanding specific programs
Lack of Trust (n=47)	Need for effective communication
	Issues with the assessment process
	Inappropriate services
	Faith in those in positions of power
Lack of Collaboration (n=31)	Necessity of a mentor
	Balance of power
	Collaboration desired by parents
Outside Resources (n=12)	Use of experts and advisors
	Importance of outside testing
Parent Feelings (n=36)	Isolation of the family
	Importance of hope
Individuals (n=19)	Positive impact on services offered
	Negative impact on services offered

It is interesting to note that some of the phrases were categorized under more than one theme. These data are presented in the following table.

Table 2

Cross-Referenced Phrase Citations of Major Themes in Interviews

Cross-Reference	Lack of Knowledge	Lack of Trust	Lack of Collaboration	Outside Resources	Parent Feelings	Individuals
Lack of Knowledge		3	2	3		
Lack of Trust	3		6		6	5
Lack of Collaboration	2	6		1	11	4
Outside Resources	3		1		2	3
Parent Feeling		6	11	2		4
Individuals		5	4	3	4	

Lack of Knowledge of the Process

The parents in this study wished that they had known what the assessment process meant, and then been given information on accommodations and services that might have been educational possibilities for their adolescents. Carey stated, "I had no understanding of what an IEP is, no understanding of what the roles of the different assessor and people at the school were and why it was being done, and even what optimum outcomes would be." The parents expressed a concern that they did not know how to put the pieces of the special education puzzle together.

Big picture. Each parent stated that she did not understand anything about special education when she began her journey. All parents in this study agreed that understanding the overall concept of the special education process is vital to parents just beginning the process. Two of the parents used the phrase, "didn't have the big picture." All three parents stated over and over that they were not informed, and didn't understand the system by which their adolescents would receive special education services. Parents felt

as if they couldn't quite put all the pieces of the puzzle together. Alice, Beth, and Carey lamented the fact that they were not informed or given information regarding special education. Alice emphatically stated, "See, that would be nice for the parents to understand. A lot of parents don't understand the difference between a 504 and an IEP." Because parents were not educated on the many facets of the special education process, each parent felt she had to search and ferret out information on her own. Two of the participants used the phrase "reinventing the wheel."

Understanding specific programs. Parents reported that they were not given information on different educational and therapeutic interventions that might be available to help adolescents. For example, Alice was never given information of the criteria to access county mental health services. She stated her erroneous belief: "Well, I don't know about it. Huh, I mean, I guess unless you're destitute, you can't access county mental health." Beth never received information on day treatment possibilities until she had lost all faith in the educational system. "And they actually, just before I took her out, they were recommending day treatment for her, which nobody had even mentioned to me before. I didn't even know what day treatment was." The school districts told parents where adolescents would be placed without conferencing with parents or seeking their opinions. The parents in this study were not informed as to why the adolescent was placed in one program over another, or the theoretical basis for the accommodation.

Lack of Trust in the Process

Each of the parents in this study began this process with hope and trust in special education to meet the student's needs. As time went on, and the child began to "fall through the cracks," trust began to falter. Alice stated, "The school is so unhelpful that I

don't, I don't even, I can't even conceive what they would ah [do]." The parents felt a lack of trust in all aspects of the special education process from identification to services offered.

Effective communication. Each parent stated that schools consistently told her that her child was "doing great." Carey reported, "'Everything's fine,' says the school district, 'everything's fine, really, look at the scores, if you look at his test scores, he's doing fine.' Okay, then why is he being held in at lunchtime all the time, and the teachers can't stand him?" At times, parents in this study could see that the adolescent was failing to thrive educationally, but were unable to convince the school of this fact because the child was making minimal academic progress. The parents lost faith in the ability of the school to attend to their child's educational needs.

Issues with assessment process. The assessment process was fraught with difficulty for all of the parents. The first issue is that parents were not given information on the assessment process. Beth stated, "Just, you know, some way of understanding what this assessment means, what it leads to, what it could lead to."

The second issue is that the parents felt that the assessments were not used effectively to determine a student's eligibility for special education. For example, Alice felt that the assessment done by the school was accurate, yet the school district reached the conclusion that the child did not need services, even though the child was seen as depressed and schizoaffective. Worse yet, Beth had an assessment done by an outside psychologist, but the school told her they would not take it under consideration.

Inappropriate services. Alice and Cary thought that the schools found ways not to offer services. The parents felt that one of the ways the school districts were able to do

this was to put off meetings. Alice, in a defeated voice, said, “The counselor, Jamie Sanders, she puts it off. We wanted it way at the beginning of the year, because of this new semester.” [The new semester began in January and the interview was conducted in March.] Also, the parents in this study expressed a concern that the mental health care that was offered was minimal or substandard. Beth explains, “And, her needs weren’t being addressed. I mean she had outpatient therapy, about half of one hour a week. For a kid who’s suicidal, it’s not enough.” They also felt that an IEP was not really individualized for the child with ED. Beth stated, “But, there’s not much creativity in IEPs, it’s all pretty cookie cutter, they plug you in, or they try to plug you in.” More often than not, parents felt that their adolescents were put in programs that did not meet the adolescents’ needs.

Faith in those in positions of power. Parents in this study never felt that they had a say in the process. The parents stated that when the adolescents first entered the realm of special education, each parent in this study put her faith in an administrator or psychologist who appeared to have her child’s best interests at heart. The parents report that as they became more knowledgeable about the special education process, it became evident that the services that were offered were not appropriate to the student’s needs. As time went on, they all lost faith in individuals within the system as well as the process in attending to their child’s needs. I could hear the anger and amazement in Carey’s voice as she stated how the school psychologist did not allow her son to receive the services he so desperately needed: “. . . It was the school psychologist . . . because everybody kowtowed to that person, and let, in most incidences, let her lead the way, and lead the discussion, and direct the discussion. And, relied on her assessments, as ill founded as

they were, to be the stopping point. It didn't matter what my psychologist said, it didn't matter what my report said, it was the school psychologist."

The parents in this study stated that the system had failed their adolescents. The parents in this study gave up on the system, and tried to do what they could outside of the system.

Lack of Collaboration

The parents did not feel that collaboration was integral to the IEP process. Initially the parents were grateful that someone in the school district took charge of the situation, but as the parents' knowledge base grew, they wanted to participate in the IEPs. Beth pondered her student's IEP process: "At the time, I had no idea about how IEPs worked. So, somebody else was writing down the goals, coming up with a plan, and I was just kind of trusting that they were telling me in their professional opinion what they know was best for her. I'm just saying in hindsight, at the time, I didn't realize how much power I had, and nobody informed me." The parents in this study felt that they were not valued for the expertise that they could give. Because of the lack of collaboration, the parents felt isolated and wished for group collaboration and dialogue either with school personnel or other parents.

Necessity of a mentor/expert. All three parents expressed the conviction that parents need to have an outside advocate, or possibly a designated person within each school to help parents navigate the IEP process. Beth implored parents "to find somebody, to find another parent, to find somebody who has gone through the process, who can act as a guide for them, and help them understand how it works."

Balance of power. All felt that the IEP was not collaborative. It was “pro-forma,” with the schools asking for feedback when they already had their minds made up on programs. The parents felt that the IEP could never be collaborative given the parent’s lack of knowledge and information. With this lack of equality in knowledge, the power swings to the school district. Beth articulated this concept well: “So, the collaboration was very out of balance. They held all the information about the criteria, about what services they had, and what the different levels of service were. I didn’t have any of that. So, it was me, just listening to them and them telling me, okay, this is what we’re going to do. With that lack of equality, no true collaboration, I don’t think, can take place.”

Types of collaboration desired by parents. The parents in the study felt that support groups would be highly helpful but were never offered. Parents desired collaboration between parents for family support. Beth did experience a collaborative process through county mental health. Her daughter received Wraparound Services, which did not include the school. “The most effective thing for her mental health treatment, was actually a thing, they were just starting this new model called Wraparound.” I asked why the school was not involved, and Beth replied, “Because she was constantly changing, her placement was constantly changing. That was so chaotic. I can’t remember anybody from any of her school placements ever being part of the Wraparound team.”

Use of Outside Resources

Alice, Beth, and Carey were able to pay experts and professionals to aid them in the quest to access an appropriate education. The children in this study had above average intellect, yet were failing in school. The parents were frustrated in their interactions with

the school district and after time could no longer envision the schools as partners in the education of the child, and so they looked outside of the school system for support. Carey spoke of experts she hired to assist her: “. . . and knew of what they were talking, and knew of what the world around special education and the options were, how to steer me, but also how to support John. And to empower me as well, to trust myself.”

Use of expert/advisor/mentors. The parents in this study used outside resources to try to facilitate their adolescents' educational achievement, as well as to address the adolescents' mental health. Parents paid for private therapists, psychiatrists, psychologists, wilderness experiences, psycho-educational assessments, temperament specialists, tutors, and consultants. Alice, Beth, and Carey enjoined parents new to this process to get outside help, to find sources of information to guide them through the process. All three parents had used Matrix at some point in their child's journey. They all highly recommend having someone to be a guide, and monitoring or mentoring a new parent. Carey stated, “There needs to be a network of people who know, who can be allies, parent allies, parent advocates.”

Importance of outside testing. Alice and Carey authorized independent educational evaluations of their adolescents. With outside psycho-educational testing, they were able to get a fuller understanding of their children. Carey also had a temperament specialist observe her son and make recommendations. Unfortunately, when presented with the information from the temperament specialist, the first grade teacher said, “You can't teach an old dog new tricks.” In this instance, a teacher was unwilling to collaborate with the parents on using effective techniques specifically suited to an individual child, which would have helped the boy to make effective transitions

from one classroom activity to the next. Outside testing is important because it helps the parent to better understand the child's needs, which in turn informs the parent as to the accommodations that might be appropriate for the child.

Parent's Feelings

Parents in this study were on a roller coaster ride of emotions. The parents all expressed an interest in parent support groups as a means to help keep hope alive as well as to share the sorrow and frustration they felt. Alice lamented, "It would be nice to have support groups for parents, too, that are similar [students with ED]. I just attended this support group of James Meyers [independent M.F.T.]; it was really interesting to hear another parent's voice than I have. Which is, you kind of have to give up. It's really hard. You have to kind of focus on giving up those academic dreams for your kids."

Isolation of the family. The parents did not think that they were regarded by the school district as being anything but a nuisance. The parents weren't able to share the concerns they had for their adolescents' education and were left to ponder the adolescents' difficulties on their own. The parents thought that they were "low on the totem pole" as far as being partners in their adolescents' education. Alice tried to communicate with the school, but reported that she was hesitant because, "I don't see the teachers see us as anything but irritating." Carey cried as she described her feelings of isolation as she strived to collaborate with therapists and teachers for effective treatment for her son: "These supports putting the blame back on me, saying this is your fault, you're doing something wrong, you are not a good mom, you need to spend more time, you need to be a better disciplinarian, but God, I'm doing that. I'm doing all that stuff, I'm being a good mom, I'm there for him. It's isolation, it's fear."

Beth said in a very small voice that one of her worst experiences was being “chastised.” All of the parents lost faith in the system. The parents reported feelings of exhaustion in trying to work with the schools. Too often, the parents were left alone with their grief and hopelessness.

Importance of hope. They all felt that one of the most important things for a parent with a child with ED is to keep hope alive. Carey repeated with conviction, many times, “I say it now, don’t give up on your kids. Don’t give up.” She spoke as if attending an IEP meeting were the same as going into battle. “To never give up on your child, no matter the adversity.” Alice talked about all of the conflicting emotions that come up when trying to keep hope alive: “Sometimes you just want to go, forget it, what is the point. Let him get whatever grades he wants, let him be a trash collector. You know, keeping a vision for the kid.” Parents all felt that it was necessary to have support systems to keep hope alive.

Importance of the Individual

The individual was the one person who either fought against giving services to the child or fought for giving services to the child. Beth reflected on the individual who negatively affected the collaborative process: “The special ed director was in charge. He was very sharp and he definitely had an agenda. He thought he knew what needed to happen. And I trusted him. But, knowing what I know now, I shouldn’t have.” On the other hand, there were those who fought for the child to receive appropriate services, and in whom the parents could trust. Alice spoke in a gentle tone of the vice-principal who was also a special ed teacher: “Yeah, she was great. Yeah, she was wonderful. I’m used to having the vice-principal being an ally.” Carey was incredulous and grateful for the

administrator who went against the school psychologist, so that her child could receive the appropriate services: “It was that administrator who was courageous enough to step up to the plate and look at the school psychologist in the face and say openly, and in front of, publicly enough, that there are no resources at this school district for my son. And it wasn’t until he said that, that all of a sudden his school counselor, kind of was kicked into motion around working with me to find, to have to meet, to help John.”

Positive Aspects

When I asked the parents the question, “What do you think are the positive aspects regarding the education of a child with emotional disturbance?” the parents seemed to search for an answer to this question. There was little that the parents could report on the positive aspects of parenting or the educational or mental health services available for the child with ED. Alice and Carey each had a positive experience with a teacher or administrator who facilitated and was empathetic to helping the adolescent receive appropriate services. Alice reported a simple academic skills class as making a difference for her child. Carey reported a moment when she was able to see a glimmer in her child’s eye after he had succeeded at a wilderness camp experience that helped to restore her faith and hope that her son could be helped. On a larger scale, Beth felt that it was a positive experience for her daughter to receive Wraparound Services, even though only county mental health, not the school district, was involved. Beth described Wraparound Services for her family: “There was a case manager and they would facilitate the meeting and when we were first starting it, they would pair up a case manager and a family partner, and they would run the meeting, and help the family

identify team members and guide everybody through the process. It was very successful with us.”

Conclusion

Alice, Beth, and Carey had adolescents with very different needs (schizo-affective, suicidal, and oppositional-defiant), yet each parent’s experiences with the special education system were very similar. They were hard put to describe a collaborative process involving mutual trust as part of the IEP. Because the parents in this study did not have knowledge of the IEP process, they felt that they never quite knew how to find the resources that each of these adolescents needed. The parents also described a system that was not effective in meeting the child’s educational needs, which caused the parents to use outside resources. Yet, on a positive note, two of the parents did have the experience of working with an individual in the school system who was competent in addressing the student’s needs. The journey of each parent in this study was one of persistence and hope for the education of an adolescent with ED.

Chapter 6

Discussion

The premise guiding this research is that parents of students with ED have knowledge and insight that is relevant and informative and yet their opinions have not been valued or heard. The research data of this study support this premise. This study addresses the parent's view regarding three major areas: the individualized education plan (IEP), collaboration, and positive and challenging aspects of educating adolescents with emotional disturbance. In this study I address six major themes that were voiced, identified, and elaborated upon by the study participants: lack of knowledge of the process, lack of trust in process, lack of collaboration, use of outside resources, parental feelings, and importance of the individual.

The emergent themes of this study reflect the findings of prior research regarding both a lack of parental inclusion and the importance of parental collaboration in the education of students with emotional disturbance. Additionally, this study supports the body of knowledge, which establishes that parents are not regarded to be knowledgeable partners in the education process while also highlighting the importance of collaboration to effectively support the education of the student with ED. The hypothesis of this study is that it is necessary to listen to parents and by doing so, add to the body of research, especially that research which illuminates parental understanding of the multitude of issues facing the parent of a student with ED.

Implications

Lack of Knowledge

One concern voiced by parents in this study was that they felt that they did not understand the IEP process. Wright and Wright (2006) have previously found that parents are confused about goals and objectives in the IEP and whether their adolescents' IEPs are appropriate. When the parents in this study were first introduced to special education, they did not voice their concerns and opinions because they felt that knowledge was held by the school system. As these parents became more knowledgeable, they grew more vocal regarding services that they felt were appropriate for their students. Additionally, parents felt uninformed by school districts regarding the various models of education available to a student with ED. The implication is that parents must be educated as to the special education process so that they may feel comfortable in participating in the IEP as knowledgeable partners.

Lack of Trust and Lack of Collaboration.

Parental responses in this study support research that has shown that the identification and assessment of a student for the classification of ED has been problematic (Landrum & Singh, 1995). Because the identification and assessment process was difficult for the parents in this study, they began to have a lack of trust in the process and the experience became adversarial rather than collaborative. Gresham (2005) found that adolescents with ED who exhibit adequate or superior academic performance often are not diagnosed with ED. As reported in this study, because their adolescents demonstrated acceptable and passing grades, both Carey and Alice had a difficult time convincing schools to assess their children for ED. As Alice stated in her interview, "It

took threatening legal action till they finally did the testing.” Furthermore, even when the assessment was done, the parents in this study did not feel their opinions were valued, or often, even considered. However, parents have the ability to report on adolescents’ friendships or the adolescents’ participation in the community, areas about which a professional may be unaware. Past research has found that parental input is necessary for an accurate assessment of the adolescent, yet often is not valued (Friedman, Leone, & Friedman, 1999). In this study, the parents indicated that they felt school psychologists who conduct the assessments hold the power in making determinations of ED. Carey remembered and voiced her concerns with the school psychologist: “. . .because everybody kowtowed to that person, and let, in most incidences, let her lead the way, and lead the discussion, and direct the discussion. And, relied on her assessment, as ill founded as they were, to be the stopping point.” Olympia et al. (2004) suggest it should no longer be the case that school psychologist be placed in gate-keeping roles. Instead, they emphasize the importance of school psychologists in taking on roles that more closely resemble those of positive facilitators.

Another area in which the parents in this study did not feel that their voice was heard was in the realm of determining effective and appropriate services for the student with ED. It is important to remember IDEA requires that specific educational programs must be developed as a collaborative effort with the parents (Lovitt, 1999). And yet, in spite of IDEA requirements, the parents in this study felt that schools made recommendations with little parental input and for this reason, made inappropriate recommendations. In fact, studies have shown that it is unlikely that the adolescents with ED are referred to systems of care or indeed receive those services to which they are

entitled (Landrum & Singh, 1995). The implication is that a more effective model must be implemented in the schools that includes parents in the decision-making process.

This study also supports what we know from literature of effective programs for the student with ED. The use of Wraparound Services has been examined extensively and found to be highly effective in remediating the problems of educating a student with ED. In this study, only Beth's child received Wraparound Services, and only because her child was actively suicidal. Beth reported that "the most effective thing for her [daughter's] mental health treatment, was actually a thing, they were just starting this new model called Wraparound." Sadly, Marin county schools and mental health agencies do not consistently implement Wraparound Services. Anderson-Butcher and Ashton (2004) remind educators and mental health professionals that "no agency or professional can succeed alone in addressing the multifaceted needs of students and their families" (p. 40).

Parental Feelings

Naseef (1989) hypothesizes that parents who participate in parent support groups have a better ability to cope with adolescents with ED. Johns et. al (2002) found that learning about others who have overcome similar adversities can help to instill a sense of hope. Alice joined a support group and when asked if she felt it was helpful, replied, "Oh yeah, wonderful." Beth found that her greatest challenge was when she was "chastised." As found in previous studies, family involvement in programs is low because of the focus on re-mediating parents' deficiencies instead of augmenting their strengths as partners in the problem solving process (McConaughy et al., 1999). This study demonstrates that most parents are left feeling exhausted, both from parenting as well as from trying to

access appropriate services for their students with ED. As Alice stated, “There is just not enough down time as a parent.” Just as a child with ED needs the support of his or her family, the family needs support from others. Parents need personal support so as to foster collaboration. Personal support for the parent also fosters hope, which enables the parent to continue with a vision of positive goals for the student. There are many ways for a family to receive support. All of the parents interviewed mentioned the importance of having a mentor or support group.

Outside Resources

As parents progressed through the IEP process, they became disenchanted and looked outside of the school system for answers and solutions to the problems that confronted their adolescents. Consequently, parents gained knowledge through private sources of information and became more vocal in expressing what they felt was needed for their child. Though an examination of the impact of using private services on parents was not made in this study, this would be an area relevant to researching when and how parents begin to have their voice effectively heard.

Importance of the Individual

A surprising finding was the power of one individual to affect the IEP process. I had not found evidence of the importance of this factor in the IEP process for students with ED in the review of literature. All of the parents interviewed identified one or two individuals within the school systems who, according to the parents, held the power in the IEP process. Typically parents felt that this individual denied services, and instead of operating in the student’s best interests, operated with regard only to the school’s interests. However, there were also those individuals within the school system who tried

to do what was best for the students and thus were able to impact the IEP process for the students in a positive manner. Parents in this study might have felt freer to express their educational concerns if they felt that the person in charge of the IEP meeting had an empathetic ear.

Limitations

The first limitation of this study is the method in which parents were found. Even though flyers were sent out, they were not distributed across the spectrum of locations where adolescents with ED are educated. This impacted the study by not being inclusive of all educational settings, especially of those parents of students who are enrolled in a special day class at the local high school. The second limitation to this study is that parents self-selected to be in the study. It is possible that only parents unsatisfied with the services their adolescents received were the ones who responded. The third limitation is that the sample size of interviewees was small. Inferences are often difficult to make with minimal sample sizes; however, with a larger sample, stronger inferences might be made as to the validity of the parent's perspective to the group of parents of students with ED as a whole. A fourth limitation is that there was only one person conducting interviews as well as coding of the interviews, which did not allow for triangulation of data.

Suggestions for Future Study

This study demonstrates the need to design future studies examining positive models of collaborative IEPs and how to effectively integrate this model into the school system. This is an important area of study because with a collaborative IEP, the parent's

voice can be heard. By examining the specific aspects of the effective collaborative IEP, a template could be devised as a guide for effective IEP meetings.

Interpersonal relationships between the parent, teacher, psychologist, and members of the IEP team should be explored. Of note in this study was the effect that one empathetic individual could have on the process. The interplay and relationships between the team members influence the IEP meeting and are important aspects for further exploration.

Conclusion

This study investigated the parent's view regarding numerous aspects of educating the child with ED. Although IDEA states the importance of collaboration between school and parent, this study did not find that such collaboration always occurs. The parental component of collaboration has often been overlooked, leaving the parent without a say in his or her adolescent's educational goals. In other words, parents are left without a voice. This study has found that parents have knowledge, enthusiasm, and can be effective partners, if schools will listen. While collaboration is an important goal in educating the child with ED, it needs to occur at multiple levels: organizational, functional, and jurisdictional (Osher, 2002). It is axiomatic that there must be a change in the system of educating students with ED. This study has significance for the general literature in that it supports current research indicating that parents are not part of the process, yet have important information to share. The family needs to be central to educational decision-making (Cartledge, Kea, & Simmons-Reed, 2002). This research points to the need of schools to listen to parents and learn from their expertise and knowledge about students with ED.

Appendix A

Institutional Review Board Forms

Approval of Research Involving Human Subjects

SONOMA STATE UNIVERSITY—INSTITUTIONAL REVIEW BOARD FOR THE RIGHTS OF HUMAN SUBJECTS

Page 1 of 6

Application for Approval of Research Involving Human Subjects

Received
11-29-05

This application is designed to fulfill the responsibilities of Sonoma State University relative to the Code of Federal Regulations, Title 45, Part 46, regarding research involving human subjects. Failure to comply with the policies and procedures referenced in this application: (1) may cause individuals to incur personal liability for negligence and harm; (2) may cause the University to lose federal funding; prevent individuals from applying for or receiving federal research funds; and prevent the University from engaging in research; and (3) will be viewed by SSU as a violation of university policies and procedures and will result in appropriate administrative action.

All research involving the use of human subjects conducted by SSU faculty, staff, or students — or sponsored in part or whole by SSU — must be reviewed and approved by the University's Institutional Review Board (IRB) for the Rights of Human Subjects prior to the start of the project and then must be conducted in full compliance with University policies and procedures. It is the responsibility of the principal investigator to refer to the IRB any project involving human subjects, even if the subjects are not considered to be "at risk." This includes research conducted in conjunction with classroom assignments that will be published or shared, as well as student dissertation or thesis. It also includes all interviews, questionnaires, surveys, observations, educational tests, and secondary analyses of previously collected data that will be incorporated into published research or other public presentation. Such projects may be undertaken only after appropriate approval and may be continued only so long as that approval remains in effect. Changes in a project, or continuation of the project following adverse or untoward occurrences during the project, are also subject to review and approval.

Research intended solely for classroom use (with no possibility of further disclosure or publication) and conference/workshop evaluation surveys do not require IRB review.

Submit applications to:

Sonoma State University, Institutional Review Board - Nichols 146,
1801 East Cotati Ave., Rohnert Park, CA 94928

NOTE: Your complete application is due one month prior to the start of your research. It should include:

- Pages one and two of this application
- A descriptive protocol
- A copy of your written informed consent form OR a request for waiver of written informed consent with a copy of the oral text you intend to use to inform your subjects of the points listed on the Checklist of Informed Consent (page 3 of this application).

Responses should be typed or printed legibly in black ink.

Your signature below certifies that:

- You have read this 6-page packet and understand your responsibilities and liabilities as a principal investigator
- You have reviewed the University's policies and procedures on research involving human subjects and will ensure your research is conducted in full compliance. Copies of the policies and procedures are available from the Office of Research and Sponsored Programs (ORSP) in Nichols Hall, Room 146. The information is also posted on the ORSP website at <http://www.sonoma.edu/orsp>
- You have completed Module 2: Investigator Responsibilities & Informed Consent) of the Human Subject Assurance Training provided online by the Office of Human Research Protections at <http://www.ohrp.hhs.gov/IRB/CERTs/AssuranceTraining.cfm>
- You, your spouse, or your dependent children have no financial interest in your project that will or may be reasonably expected to bias the design, conduct, or reporting of your research.

Signature of Principal Investigator: Susan Milner Date: 11/29/05

Title of Project: Recording the Parent's Voice - Listening to Parents of Children with Emotional Disturbance

Name of principal investigator: Susan Milner Telephone: 415-261-4318

Home Address: 610 Via Castas, Greenbrae, CA 94904 Email: susan_milner@sbglobal.net

Department: Education Title or Academic Status: Student

Co-Investigator(s): None

For student investigators only:

Please print or type name of professor or faculty advisor: Dr. Mary Dingle

Signature of professor or faculty advisor: [Signature] Title or Academic Status: Professor

Department clearance: N/A Date: 11/29/05

Student investigators must obtain clearance from their department's human subjects committee, if one exists. Psychology students are required to obtain the signature of the department chairperson.

Last Name: Miltner

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Protocol Summary Sheet

If requesting Exemption or Expedited Review, specify category (see Appendix B):		Title of Project: Recording the Parent's Voice - Listening to Parents of Children with Emotional Disturbance		
Brief description of purpose of project: The purpose of this project is to interview and record the thoughts, observations, and ideas of parents of children with Emotional Disturbance, regarding the Individualized Education Plan (including assessment) for special education, collaboration between institutions and parents, and the positive and challenging aspects of the process. With the information gathered from parents, I will then present my findings to parents, teachers, and agencies within group settings.				
<input checked="" type="checkbox"/> New project	<input type="checkbox"/> Modification	Date Starting Interaction with Human Subjects:	End Date:	Funding Source (if any):
<input type="checkbox"/> Sub-study	<input type="checkbox"/> Previous study	January 1, 2006	September 1, 2006	None
Subjects				
Number: 4-12		Population: Parents of Student's with Emotional Disturbance		
Source/How contacted: I plan on distributing flyers to Matrix, Marin County Office of Education, Marin County SELPA, Marin County Mental Health, and Sonoma County Office of Education, all agencies that work with parents of students with emotional disturbance. In turn, these organizations will distribute the flyers requesting parent participation in my master's project.				
Instruments				
Check all that apply: <input type="checkbox"/> Tests <input type="checkbox"/> Questionnaires <input checked="" type="checkbox"/> Interview guides <input type="checkbox"/> Other: _____ Attach one copy of each instrument used. If not yet developed, provide drafts, samples, and/or outlines				
How administered: <input type="checkbox"/> Telephone <input type="checkbox"/> Mail or email <input checked="" type="checkbox"/> In person Length and frequency of procedure: one interview of approximately one hour in length.				
Data				
Check all that apply Data will be recorded by: <input checked="" type="checkbox"/> written notes <input checked="" type="checkbox"/> audio tape <input type="checkbox"/> video tape <input type="checkbox"/> photography <input type="checkbox"/> film <input type="checkbox"/> other: _____				
Data will include: <input type="checkbox"/> information which can identify the subject (e.g., name, social security number, other unique identifier) specify: NO <input type="checkbox"/> codes linked to subjects name by separate code key <input checked="" type="checkbox"/> codes not linked to subjects names				
For items checked above, circle box of those related to data that will be reported				
Data will be used for: <input type="checkbox"/> publication <input type="checkbox"/> evaluation <input type="checkbox"/> needs assessment <input type="checkbox"/> thesis <input checked="" type="checkbox"/> other master's project to be presented to organizations, teachers and parents involved with students with Emotional Disturbance.				
Informed Consent				
<input checked="" type="checkbox"/> written (attach copy of consent form; see attached sample and checklist)				
<input type="checkbox"/> oral (attach text of statement and request for waiver of written informed consent; see Appendix A)				
THIS SPACE FOR IRB USE ONLY				
This project: <input checked="" type="checkbox"/> is exempt under category A- <u>2</u> <input type="checkbox"/> is eligible for expedited review under category B- _____ <input type="checkbox"/> requires CRHS review				
		Human Subjects Administrator	Date	
		Duane Dove	2/6/06	
		Chair, IRB	Date	
Comments: <i>Your Project is approved.</i>				

If you have any questions, contact the Office of Research and Sponsored Programs at 664-2448.

Human Subjects Protocol

1. What are your research objectives?

My research objectives are twofold.

1. To interview parents and get their perspective on the assessment process, Individualized Education Plan (IEP), collaboration with mental health and educational agencies, and positive and/or challenging aspects regarding the education of their child with emotional disturbance.

2. Develop a presentation that summarizes what I learn from the parent interviews to present to agencies involved with families that include a child with emotional disturbance.

2. Discuss the significance and scientific merit of the study.

This thesis is significant because the input of parents has been undervalued within the IEP process. This is particularly the case with parents with students with emotional disturbance. This thesis will add to the body of knowledge about the issues of parents of students with emotional disturbance. This will assist my work in advocating and supporting students with emotional disturbance within the educational setting.

The information I gather from parents will be essential to the creation of a presentation that I will give on emotional disturbance from the parent's point of view. Within the field, often the parent is not recognized as an expert of their own child. Hopefully, this thesis will increase the recognition of the parents as an equal partner in the educational process.

3. In what manner and to what extent will human subjects be involved?

I will be interviewing the parents of students with emotional disturbance for approximately one hour. I will record their voice, as well as take notes during the interview.

4. What procedures, instruments, etc. will be employed?

I will use an audio recording device. I will also use an interview guide. I have attached a list of questions that will guide my interview process.

5. What existing data, if any, will be used?

No existing data will be used.

6. What will the subjects be told about their involvement in the study?

I will inform them that I am interested in recording and listening to their view on the assessment of their child for emotional disturbance, the Individualized Education Plan, collaboration with mental health and educational agencies, and positive and/or challenging aspects regarding the education of their child with emotional disturbance. I will tell them that I plan on sharing my findings to parents, teachers and appropriate agencies. I will assure them that their names will not be used.

7. Describe the procedures for obtaining and recording the informed consent of subjects.

Attach a copy of the consent form if written consent is planned. If oral consent is planned, attach a copy of the test of the statement and a request for waiver of written consent.

I plan on giving the parents a copy of the written consent form before interviewing them. Once they have signed the consent form, I will begin the interview.

8. Describe any potential risks to the subjects, including psychological stress and physical hazards. How are these risks outweighed by the sum of the benefits to the subjects and the importance of the knowledge to be gained?

It is possible that the interview questions might trigger some psychological stress in the parent regarding the fact that their child has an emotional disturbance or that the parent does not feel that their child is receiving appropriate services. There may be unforeseen dialogue that will impact the parent. I will discuss these issues with the parent to the best of my ability. I will leave time at the end of the interview to address any questions or concerns parents might have. I will also give the parents my email, so that they can contact me and discuss any issues that have made them uncomfortable.

The risks are outweighed by the benefit to the parent. The parent might benefit by realizing how important their own personal knowledge is to the education of the adolescents with emotional disturbance.

9. Describe any interventions or manipulations of subjects or their environments.

There will be no interventions or manipulations of subjects or their environments.

10. What measures will be taken to safeguard the welfare of subjects, their right to privacy and confidentiality of information?

The subjects will be coded and the codes will not be linked to their names. I will keep the notes and recordings on our interview locked in my safety deposit box at the Bank of America in Greenbrae, CA. No names will be used in any publication, public statement, or presentation based on the study. Any information that is obtained in connection with this experiment will remain confidential and within the requirements of the law.

11. Are school-age adolescents or other minors to be involved? If so, please describe the subject population.

There are no school-age adolescents or other minors involved.

12. Are psychological tests to be used? If so, please name them.

I will not be using psychological tests.

13. Describe the debriefing of subjects. What steps will be taken to deal with the after-effects of emotional stress resulting from the research procedure?

There will be an opportunity to discuss the subject's feelings at the end of the interview. They will also have my email and phone number, if they should need to contact me and discuss the interview.

14. What procedures will be taken to insure prompt reporting of (a) proposed changes in the activity, (b) any unanticipated problems involving risks to the subjects or others, (c) any injury to subjects, and (d) any non-compliance with policies and procedures?

I will promptly contact by phone, both my Committee Chair, Dr. Mary Dingle, and Sonoma State University's Institutional Review Board for the Rights of Human Subjects. Since I am the sole interviewer, I will have a great deal of control over the project.

I will strictly adhere to the policies and procedures of the human subject protocol.

15. What type of remuneration, if any, will be offered to subjects for their participation in the research?

There will be no remuneration offered to subjects for their participation.

Informed Consent

You are invited to participate in a research study of parental views of the Individual Education Plan process and services provided for students with emotional disturbance being conducted by Susan Miltner of Sonoma State University. This research is being done in partial fulfillment for my master's degree. The purpose of this research is to add to the body of knowledge about the issues of parents of students with emotional disturbance. I plan to compile data from multiple parent sources and then present this information to agencies, parents and teachers that work with adolescents with emotional disturbance.

If you decide to participate, Susan Miltner will interview you for approximately one hour. During this interview I will make an audio recording and take notes. This is your chance to discuss issues and talk about things that matter to you. It is possible that the interview and questions might make you uncomfortable. You do not have to answer any questions. There will also be an opportunity to discuss your feelings during and at the end of the interview. You will be given my email and phone number and may contact me at any time with your concerns. I cannot and do not guarantee or promise that you will receive any benefits from this study.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. I will use a code that is not linked to your name to protect your privacy. I will keep the notes and recordings on our interview locked in my safety deposit box at the Bank of America in Greenbrae, CA. Any information that is obtained in connection with this experiment will remain confidential and within the requirements of the law.

Your participation in this study is completely voluntary. Your decision whether or not to participate in this study will not prejudice your child's current or future services within their school district or yours or your child's future relations with Sonoma State University. There is no penalty for refusal to participate. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time, without prejudice. If you have any questions please ask us. My name is Susan Miltner and I can be reached at 415-261-0318 or susan_miltner@sbcglobal.net. You may also contact my faculty advisor, Dr. Mary Dingle at 707-664-2433 or mary.dingle@sonoma.edu.

I appreciate your willingness to consider being a participant in this study. By signing this consent form, you will indicate that you have decided to participate having read the information provided above.

NAME (Signature):

NAME OF PRINCIPAL INVESTIGATOR (Signature):

DATE:

Appendix B

Parent Invitation Flyer

Invitation to have your voice be heard!

To: Parents of adolescents with emotional disturbance

Project - to interview parents about:

- Assessment
- Individualized Education Plan (IEP)
- Collaboration
- Positive or Challenging aspects of educating a child with emotional disturbance

Presentation - With the information gathered from parents, I will then present my findings to parents, teachers, and agencies within group settings.

Why - to help other parents navigate the educational system and to help you recognize your own knowledge base.

Goal - to increase the collaboration, dialogue and understanding between parent to parent and parent to teacher so as to enhance the educational opportunities for the adolescent with emotional disturbance.

How - If you are willing to talk with me, the interview will take approximately one hour of your time. You may choose the place that is most comfortable for you to do the interview.

To participate, **contact**:

Susan Miltner
415-261-0318
susan_miltner@sbcglobal.net

I am currently enrolled at Sonoma State University in the Masters of Education Program and your **confidential** interview will be included in my master's project.

You will receive a list of resources available on the Internet.

Appendix C

Interview Guide

Assessment

Please tell me about your experiences with the assessment process in special education.

Probes:

- What types of information do you think is necessary for the parent to have before beginning the assessment process?
- What would you have liked to be included in the assessment report, which was not included?
- What types of information did you provide in the assessment of your child?
- How do you think the assessment report portrayed your child?

Individualized Education Plan

What has your experience been with IEP development and the IEP meeting?

Probes:

- Who do you feel has the most responsibility for setting IEP goals and why?
- What ideas for educational goals did you bring to the IEP?
- How does the administrator include you in the IEP meeting?
- How do you think mental health services should be addressed in the IEP?

Collaboration

How do you define collaboration? Please describe your collaboration with school and mental health staff.

Probes:

- What would further positive interaction between you and the school district?
- How do you and the special education teacher communicate?
- How do you feel about the collaboration between county mental health and the school?
- How do you feel about the collaboration between county mental health and the parents?

What do you think are the positive or challenging aspects regarding the education of a child with emotional disturbance?

Probes:

- In what areas do you feel you need more education in?
- What have been your greatest challenges?
- What has been the most helpful service or component in the education of your child?
- What advice would you give to parents just beginning this process?

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