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## CONVERSATIONS WITH FORMER STUDENTS WITH INTELLECTUAL DISABILTY AND THEIR FAMILIES ABOUT THEIR EXPERIENCES IN HIGH SCHOOL

By

### FRANCES ROBINSON DUFF

B.A., Psychology, New York University, 1969 M.A., Special Education, The University of New Mexico, 2005

### DISSERTATION

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy Special Education

The University of New Mexico Albuquerque, New Mexico

May, 2013

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### **Dedication**

"A dream you dream alone is only a dream. A dream you dream together is reality"

John Lennon

To Asa, my husband,
Thank you for dreaming with me.

### Acknowledgements

This has been a long journey that I could not have undertaken nor completed alone.

I am grateful to my husband, Asa, for the many days that stretched into years when he granted me the quiet I needed to proceed and for arguing with me when I doubted myself.

I am grateful to my daughter, Cristin, for keeping me in touch with reality, for helping me to see that each step brought me closer to my goal.

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I am grateful to Phillip Contreras who bounded into my life and started me on this journey.

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### **ABSTRACT**

Collaboration among parents, educators, and students expands the knowledge base and promotes mutual respect among decision-makers involved in planning students' education. The relationship can help students achieve their goals. This study sought to examine the experiences among students with intellectual disability and their families in high school. I chose to use qualitative methods of portraiture and interpretative phenomenological analysis (IPA). Students, like those in this study, with low incidence disabilities are often disenfranchised because of their low proportion of the general population of high school students. The results of this study, reported in portraits, gave voice to members of this disenfranchised group. I interviewed three former students, their mothers, and one adult sister. I recorded, transcribed, and analyzed the interviews. I reported the results as portraits to capture the voices and document the lived experiences of this marginalized group. There were a few notable common threads among the participants. The former students were all assigned to small group, special education classes and included only in a few general education electives. Despite negative experiences, each former student said that he liked school. The former students' mothers reported that the quality of

education that their sons received was dependent on the quality of individual teachers. The mothers expressed that the IEP meetings were not helpful to them or their sons, but were carried out to serve the needs of the system. A third commonality among the mothers was that they did not receive appropriate transition services from the school district. Generalization of the study is limited by the small sample size and the unique nature of each portrait. However, a clear picture emerges of the experiences of these individuals during their high school years.

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### Chapter 1

### Introduction

When parents, educators, and students cooperate in planning educational outcomes, the results reflect a collaboration of all the parties who have a vested interest in the education of the child. Because each member of the team has been able to contribute, the bank of knowledge expands and communication lines open and function effectively. Misunderstandings can be avoided or clarified and mutual respect is developed as a foundation for future collaborative efforts. Partnerships between parents and teachers can help students achieve their goals in a healthful and supportive environment (Fish, 2006, 2008; Johnson, Duffett, Farkas, & Wilson, 2002; Risko & Walker-Dalhouse, 2009; and Worcester, Newman, Mendez, & Keller, 2008). This study is intended to capture the voices of former students with intellectual disability and their families as they recount their stories of interaction with school systems during the students' high school years. I conducted interviews with three former high school students, their mothers, and one adult sister. Using methods garnered from portraiture and interpretative phenomenological analysis, I examined their words and reported my findings as individual portraits of the participants.

This chapter is divided into six parts: Legal requirements for parent and child participation, the role of teachers, qualitative research, theoretical position, definitions of terminology, and purpose and significance of this study.

### Legal Requirements for Parent and Child Participation

Individuals with Disabilities Education Improvement Act (IDEA) does not provide clear delineation between the rights of the child and the rights of the parents. According to Grover (2007)

It must be recognized that although the illusion is created that education is regarded as a child's right, in fact, legislatively and judicially the right is generally treated as a parental liberty right to have the child educated according to parental wishes within the general minimum standards set out by the state (p. 61).

The law, in conformance with American traditions of parental control of their children, appears to conflate the rights of the child with the rights of the parents. The U.S. Supreme Court in Winkelman v. Parma City School District (2007) interpreted IDEA to include provisions granting parents' rights to represent their child's interests in an IDEA case. The United Nations recognizes the pivotal role of families. A World Fit for Children reported "The primary responsibility for the protection, upbringing, and development of children rests with the family" (Sec. 15). At the same time, however, the Conventions and other documents repeatedly state that the child has a right to be heard and her view given due consideration. Other than the mention of including a child in her IEP meeting (U.S.C. 1414 (d) (1) (B) (vii)), IDEA does not recognize the voice of the child in determining educational programs. There is an assumption that parents will act in the best interests of the child. At the high school level, students often have the maturity to make decisions regarding their education. Teachers have a moral—if not yet legal—obligation to listen to the students. High school students have a clear picture of a school's culture and climate and are, therefore, better able to judge their place in the school community. If we fail to listen to their concerns and ideas, we are eliminating an important source of information in the decision-making process.

The United Nations recognizes the rights of children to rest, to engage in play and recreational activities (United Nations General Assembly, 1989). IDEA similarly requires that children with disabilities have the right to recreational activities. In addition to academic

requirements, the IEP must contain statements of supports or modifications that will allow the child "to participate in extracurricular and other nonacademic activities" (§ 1414 (d) (A) (IV) (bb)). This recognizes that play or other related activities are important to the development of the child and should be an important part of school life (Ginsburg, 2007).

Special education programs reflect district and school informal practices. Although IDEA both requires and encourages family participation, the reality of the processes, particularly those in Individual Education Plan (IEP) meetings, most often casts families in passive roles (Valle & Aponte, 2002). IDEA contains clear and specific directives about parent-professional partnerships. Congress unequivocally presented in its findings that

Education of children with disabilities can be made more effective by strengthening the role and responsibility of parents and ensuring that families of such children have *meaningful* [emphasis added] opportunities to participate in the education of their children at school and at home (20 U. S. C.§ 1400 (C) (5) (B)).

By listing parents first as members of the IEP team, IDEA underscores the importance of parents' involvement in the process (20 U. S. C. § 1414 (d) (1) (B) (i)). IDEA provides extensive procedural safeguards for student and parents including the right of parents to participate in meetings. Federal regulations elaborate on IDEA:

Each public agency must take steps to ensure that one or both of the parents of a child with a disability are present at each IEP Team meeting or are afforded the opportunity to participate, including notifying parents of the meeting early enough to ensure that they will have an opportunity to attend; and scheduling the meeting at a mutually agreed upon time and place (34 CFR § 300.322 (a) (1-2)).

Additionally, "the public agency must take whatever action is necessary to ensure that the parent understands the proceedings of the IEP team meeting" (§ 300.322 (e)). If these statutes and regulations are violated, parents' participation in their students' educational process may be limited.

IDEA requires that parents be informed of their rights and the procedural safeguards that are in place. The procedural safeguards are rife with legal and educational jargon that can be difficult to fathom. Fitzgerald and Watkins (2006) examined the readability level of documents presented to parents and concluded that 90% of those documents were beyond the reading level of the average person with many being written at the college level or higher. Perhaps, then, simply providing parents with copies of the procedural safeguards is not adequate to give parents equal standing in the planning and implementation of their children's educational program.

Generally, parents are at a disadvantage when dealing with schools and districts, because ultimately the decision making power lies in the hands of school personnel in whom resides pedagogical expertise. Blau (2007) contended that IDEA provided parents with "little more power than was necessary to approve or disapprove the recommended services, veto power to refuse them, and a 'voice' to provide input in recommending alternative services; a voice, many felt, that was not often heard outside the due process protocol" (Sec. III, para. 4). As parents continue through the educational system, barriers accumulate and become more difficult to surmount.

### Role of Teachers

Teachers have an obligation to include parents and families as equal partners in their children's education. Murphy (1995) stated that "collaboration means that professionals learn

from families as well as instruct them. When collaboration is a major component of familyprofessional interaction, such interactions are more likely to be substantive, rather than just superficial" (p. 27). Parents are at an initial disadvantage when confronted by a team of experts, namely, teachers, administrators, related service providers, counselors and other school and/or district personnel. Teachers, who are the common link between families and schools, need to be aware of their role in providing meaningful ways to include parents in the educational decisions for their children. Baum and Swick (2008) claimed that "teachers need to see families as meaningful contributors to their child's education, whose knowledge, opinions, and concerns are a valuable and critical component of the educational process" (p. 580). Special education teachers should be in the vanguard of advocacy for the children in their care and their families. The need for family involvement is especially acute for families of students with disabilities (Blue-Banning, et al., 2004; Knight & Wadswirth, 1991; Murphy, et al., 1995; Ratcliff & Hunt, 2003; Spann, et al., 2003; Stoner, et al., 2005; Van Haren & Fiedler, 2008; and Yoshida, Fenton, Kaufman, & Maxwell, 1994). Teachers need to become allies as well as experts in planning and providing appropriate services for students with disabilities and their families. In Pruitt, Wandry, and Hollums (1998), parents asserted that if teachers knew the families better they would be better able to incorporate their knowledge and understanding into the individual plans for their children. The researchers cited parents who desired to be treated humanely when talking about their children who wanted to be treated with honesty and dignity.

Students, especially those with intellectual disability, may sometimes go unheard or even unnoticed in the flurry of discussions at an IEP meeting. Teachers are unquestionably in control and can determine a child's fate from day to day. Reid and Burton (1995) called students with disabilities the "forgotten element in the educational equation" (p. 607). Teachers who try to be

helpful offer strategies and advice, but rarely ask students for their input into their own learning. Curtin and Clarke (2005), based on research with students with disabilities, stated that "Listening to what young people with disabilities have to say about their education experiences is one way in which to determine how best to support their needs" (p. 199). Keefe, Moore, and Duff (2006) considered students the experts in their own education, finding insight in their experiences and wisdom in their words. It seems illogical, but many teachers do not consider that students who do not appear to be learning may be able to tell them why they are failing.

### **Teacher Preparation**

Special education teachers who have a unique relationship with parents of students with disabilities should be required to have extensive knowledge and skills in understanding and working with families. IDEA requires schools to promote the equal participation of parents in the planning of a child's education program. Special education teachers must carry that banner into the everyday operations of planning and implementing IEPs. Special education teacher preparation programs should look beyond the licensing requirements and offer new teachers opportunities to develop expertise in family and community involvement. The National Board for Professional Teaching Standards (NBPTS) presents a comprehensive explanation of what is expected of an accomplished special education teacher. Preparing "accomplished" rather than just "licensed" teachers should be the aim of teacher preparation programs. Based on National Board for Professional Teaching Standards (NBPTS) standards for family partnerships a teacher preparation program in special education should provide sources of knowledge about the interrelatedness of families, culture, communities, socioeconomic status and the lives and schooling of the children in their care (NBPTS, 2010).

### **Qualitative Research**

I chose to conduct qualitative research instead of quantitative methods despite the fact that quantitative data is given preeminence in the current political agenda for research. The No Child Left Behind Act (NCLB), supported by the National Research Council's (NRC) Report on Scientific Research in Education, has established positivist, randomized designs as the "gold standard" (Hendry, 2010, p. 74) of educational research. The overreaching emphasis on standardized testing to evaluate and regulate all aspects of education is an indication of this dependence on quantitative data as the basis for making policy decisions.

The underlying paradigm for quantitative research is positivist, a paradigm in which it is assumed there exists a fixed reality that can be observed and measured and that is objective and value free. Qualitative inquiry embraces the concept of reality as socially and psychologically constructed, dependent on the relationship between the researcher and what is studied, and value laden (Charmaz, 2008; Creswell, 1998; Davis, 2007; Demarath, 2006; Denzin & Lincoln, 2008; Denzin, et al., 2006; Eisenhart, 2006b; Firestone, 1987; Freeman, deMarrais, Preissle, Roulston, & St. Pierre, 2007; Gelo, Braakman, & Benetka, 2008; Greenwood & Lowenthan, 2005; Henwood & Pidgeon, 1994, 2003; Lather, 2004; Lincoln & Cannella, 2004; Ryan & Hood, 2003; Schiellerup, 2008; Simmons, 2007; St. Pierre & Roulston, 2006; and Wright, 2006). Quantitative inquiry relies on methods from the natural sciences using measurement and statistical analysis. Qualitative inquiry relies on naturalistic settings and humanistic methods in attempting to gain understanding of individuals within social science frameworks. Unlike quantitative research, qualitative research employs methods that are non-manipulative; the researcher seeks answers that are not affected by experimental treatment.

The voices of former high school students and their parents bring stories of lived experiences to those who listen. Qualitative research methods provide the clearest method of giving voice to those experiences. Qualitative research allows the researcher access to meaningful accounts of participants' experiences in their personal, societal, cultural, historical, and sometimes political contexts (Charmaz, 2008; Creswell, 1998; Denzin & Lincoln, 2008; Eisenhart, 2006a: Henwood and Pidgeon, 1994; Mills, Bonner, & Francis, 2006; Odom, Brantlinger, Gersten, Horner, Thompson, & Harris, 2005; Simmons, 2007; Slekar, 2005; Stake, 2008; and Thomas & James, 2006). According to Eisenhart, "Qualitative data are powerful" (p. 567). Qualitative inquiry recognizes the knowledge and experiences of marginalized people. Individuals with disabilities have historically been segregated from the mainstream of society (Bucciere & Reel, 2010). Qualitative research has the capability of giving voice to and honoring such individuals.

Portraiture. Portraiture can be a valuable and creative way to present research and potentially to effect social change. If portraiture can reach the aesthetic standards of fictional and non-fictional literature, the level of influence it can achieve would be powerful and long-lasting. The works of Robert Edgerton (*The Cloak of Competence*) or Jonathan Kozol (*Savage Inequalities*) or Stephen Jay Gould (*The Mismeasure of Man*) leave lasting impressions on large numbers of individuals, including administrators and policy makers. Literary authors, through their ability to weave language into stories, present subjects of eminent importance in ways that leave indelible images. We came to see the devastation of colonization in Chinua Achebe's *Things Fall Apart*; the ultimate consequences of hatred and cruelty in Elie Wiesel's *Night*; the absurdities of institutionalization in Ken Kesey's *One Flew Over the Cuckoo's Nest*—each author and each book

carrying with it the ability to open minds and change hearts—and ultimately rectify injustice by speaking truth to power. This is the intrinsic power of art.

Lawrence-Lightfoot and Davis (1997) defined portraiture as

A method of qualitative research that blurs the boundaries of aesthetics and empiricism in an effort to capture the complexity, dynamics, and subtlety of human experience and organizational life. Portraits seek to record and interpret the perspectives and experiences of the people they are studying, documenting their voices and their visions—their authority, knowledge and wisdom (p. xv).

Portraiture depends on the nature of stories to capture a holistic view of the participants in the study. What should not be disregarded in recognizing the potential aesthetic qualities of portraiture is that it is a valid method of qualitative inquiry. Lawrence-Lightfoot and Davis called it a "disciplined, empirical process—of description, interpretation, analysis and synthesis..." (p. 185).

In desiring to present the stories of parents and former students, I will attempt in this study to create articulate and evocative portraits. There are stories of struggles and frustration, but there are also stories of triumph as well, when students and parents overcame obstacles and created new realities for their lives after high school.

Interpretative phenomenological analysis. Smith (2004) stated that Interpretative Phenomenological Analysis (IPA) "aims to explore in detail participants' personal lived experience and how participants make sense of that experience" (p. 40). Two characteristic features of IPA as designated by Smith are that it be idiographic and inductive. Like portraiture, IPA's focus is on "the participants' personal and lived experiences and how they make sense and meaning from those experiences" (p.48). In the tradition of good qualitative research, IPA does

not "seek to find one single answer or truth, but rather a coherent and legitimate account that is attentive to the words of the participants" (Pringle, Drummond, McLafferty, & Hendry, 2011, p. 23). Shaw (2011) saw in IPA a "commitment to making sense of the cares and concerns of the individuals living their daily lives, bound by the circumstances in which they find themselves" (p. 29). In its aspects of honoring the individual lived experiences of the participants, IPA is a practical complement to portraiture, especially in its use of the semi-structured interview as the basis of data collection.

### **Theoretical Position**

Through a critical theory lens, I see the special education population of a school as a distinct class, struggling to gain acceptance and to partake equally in the advantages of the majority population of general education students. The history of special education is replete with examples of segregation and repression. In addition to recognizing the power discrepancies in education, I also want to transform the system and "give voice to the unheard and power to the marginalized" (Strawn, 2009, p.37).

In approaching this study, I attempted to recognize possible biases in myself and worked to reduce them and prevent them from distorting my research. I have experienced students with disabilities and their parents who have been silenced—and in some cases continue to be silenced—by powerful bureaucracies that control school systems. It has taken an inordinate amount of time, legislation, and litigation for students with disabilities to find a measure of relief from long-standing neglect and oppression from educational and political systems. Marcuse (2010) indicated that "All forms of resistance, but particularly critical strategic resistance, are a threat to the smooth functioning of the system, and historically have brought forth measures for their control" (p. 360). Current conflicts with funding to meet the real needs of students with

disabilities reflect the power of the institution to maintain its dominance over a marginalized group. Funding, often a hegemonic excuse for maintaining the status quo, can force students with disabilities to accept reduction in services that further separate them from the benefits of the larger society. School boards, district and state bureaucracies determine allocation of funds and therefore exercise "control over who gets what and who decides with regard to the distribution of resources and funding" (Nguyen, 2010, p. 346). Current regulations that require standardized testing not only allocate hundreds of millions of dollars to testing (Phelps, 2000) instead of to students but also further relegate special education students to the disaggregated sub-group that cannot meet the requisite scores. A glimmer of hope is arising in the collective voices of teachers about the intrinsic unfairness of high-stakes testing (Lauermann & Karabenick, 2011). Such voices indicate that transformation is possible.

My intent in undertaking this study was to reveal the voices of those who are members of a social class without the automatic privilege of those without disabilities for whom our educational system was designed. However, a greater purpose was my hope to shine a light on our system and to share my dream of equity in education. Dreaming, according to Leonardo (2004), is "a sincere search for alternatives and not the evasion of reality...a refusal to surrender to despair" (p.15). Institutional barriers can be brought down.

There is a large body of critical race theory research. I propose that much of what is offered can be transferred to a new category, perhaps designated as critical disability theory. There is some justification in this transference in the understanding that statutes designed to protect students with disabilities have emanated from *Brown v. Board of Education* (1954). This Supreme Court decision that played a part in the struggle to rectify racial segregation, laid the groundwork to rectify disability segregation. Students with disabilities can be seen as a

disenfranchised minority whose struggles mirror, in some ways, those of racial minorities. They, too, have suffered discrimination, bigotry, and segregation. Chapman (2007) asserted that critical race theory "decenters the prominent position of class and socioeconomic status...and repositions race as the primary lens" (p. 157). I propose that critical disability theory can reposition disability as the primary lens in research in special education.

### **Definitions**

Intellectual disability. Intellectual disability as used in this study is defined by the American Association on Intellectual and Developmental Disabilities: "Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18" (Schalock, *et al.*, 2010, p.1).

Former high school students. Students who have completed at least four years of high school and have graduated or received certificates of transition. Some students remain in schools until they reach age 22; others follow procedures and timelines similar to their nondisabled peers.

### Purpose and Significance of This Study

The purpose of this study is to give voice to former high school students with intellectual disability and their families about their experiences in high school. The study is intended to present recollections of the lived experiences of these individuals with an eye toward presenting their stories as counter balance to the unrelenting demands for compliance with requirements created by a bureaucracy distant from the day-to-day reality of most school environments.

In the current climate of education, policy makers rely inordinately on standardized test data. Such data are limited in scope and present a narrow, dehumanized snapshot of students. What are ignored are the real experiences of families and students who are directly affected by state, district, and school policies. Students with low-incidence disabilities such as those with intellectual disability have no strength in numbers to challenge the status quo. I hope that this study allows the voices of this underrepresented minority to be heard by those who have the power to make change.

### Chapter 2

### **Review of Relevant Literature**

This chapter is divided into three main sections, each of which is divided into further subsections. The section on parents' rights includes IDEA and recent Supreme Court decisions. The section on students' rights includes United Nations and IDEA. The final section, the role of teachers and teacher preparation includes knowledge of the law and collaboration with parents.

The history of special education law demonstrates the recognition of the role of parents in the education of their children. In the most recent iterations of the law, the significance of parents' role in the educational planning for their students in special education has been clarified and underscored.

### Parents' Rights

IDEA. With the inception of IDEA, parents of children with disabilities were granted more specific rights over the education of their children. Parents were considered equal partners with the schools in developing the appropriate programs and services for their children. IDEA brought parents of students with disabilities into more frequent and intensive contact with their children's schools. The increase in parental participation is undoubtedly of benefit to the children, but that participation has frequently been the source of conflict between parents and schools. LaNear and Frattura (2007) suggested that despite favorable decisions, based on "majoritarian logic" (p. 92), the implementation of laws and rulings in special education do not necessarily fulfill our obligations to children with disabilities. They recommended that we turn a more critical lens on the processes and begin to "consider not only 'what's fair,' but more importantly, 'what's right" (pp. 105-106).

In addition to guaranteeing the right of a child with a disability the right to a free and appropriate public education (FAPE), IDEA (2004) sought to ensure that parents' rights and the rights of their children with disabilities were specified and implemented fairly by providing procedural safeguards (20 U. S. C. § 1415).

The law requires schools to allow parents the opportunity to examine all records relating to their children. According to the statute, parents have the right to participate in all meetings, not only IEP meetings, concerning the education of their children. Parents are entitled also to a timely and detailed written notice of any action that the school proposes regarding the education of their child with a disability. This prior written notice must include a description of the action being considered and an explanation that includes specific information about what was used as a basis for the school's proposed action. Parents have a right to examine the information that the school is considering. The notice must also contain enough information so that the parent can assess the proposed action including other options that were considered and why they were rejected, and other factors related to the action that the school is considering. In order to assist parents in understanding the complex decision-making process, the school must provide information about sources that the parents may access for further clarification.

IDEA requires that parents be informed of their rights and the procedural safeguards that are in place and be "written in the language of the parents and written in an easily understood manner" (20 U. S. C. § 1415 (d) (2)). Federal regulations refine this requirement to a notice that must be "written in language understandable to the general public' (CFR § 300.503 (c) (1) (i)). Fitzgerald and Watkins (2006) cited earlier, applied readability tests and found that 90% of the documents containing the procedural safeguards did not meet this criterion. Subjected to a specific test of readability, "20% of Parents' Rights documents were written at the

college level or higher. [A second test of readability] showed that more than 50% of the documents were written at the college level or higher" (p. 506). These readability levels can have a deleterious effect on parents' ability to comprehend their rights. If schools desire to include parents as equal partners, they must inform parents and assure their understanding of their rights under the law.

Irrespective of parental rights and procedural safeguards provided by IDEA, educational decisions still fall within the purview of educational experts, to whom even the Court defers for expertise (*Shaffer v. Weast*, 2005). The mere existence of IDEA and the reauthorizations and amendments suggest that schools are not adequately addressing the needs of students with disabilities. If they were, there would be no need for a federal statute to ensure that those needs are met in American schools.

A brief overview of the IDEA document alone demonstrates areas in which conflicts are probable. Lake and Billingsley (2000) described conflict in terms of circumstances that generate negative feelings between parents and school personnel. They conducted interviews with 22 parents in Massachusetts. Their findings indicated that the most frequently cited factor that was a basis of conflict was the difference between how the school perceived the child and his needs and how a parent saw her child. Parents recognized their child's positive aspects while schools more often addressed the child's deficits. Parents were frustrated by the school's emphasis on what a child could not do and believed that the school's point of view was reflected in the child's placement and program. Lake and Billingsley pointed out that "the lens chosen determines what is seen as problematic and what receives attention" (p. 244). Other areas where conflict was provoked were an imbalance of knowledge, especially information that would help parents effectively advocate for their children; quality and delivery of special education services;

constraints on resources; lack of validation of the parents' role in the process of planning; issues of communication including a lack or infrequency of exchanges between the school and parents, and a perception that information was withheld; and broken trust.

Most of these challenges to successful collaboration can be avoided by maintaining a mutually respectful relationship between parents and the school. Teachers who keep parents in the loop can head off disagreements before they develop into controversy. Lake and Billingsley recommended that educators should "develop strong, reciprocal relationships with children and parents…use good communication skills…provide a foundation for satisfying and productive relationships" (p. 249).

IDEA provides for shared-decision making between parents and the school. Often the reality of this relationship belies the equal footing that the law requires. Not all parents are equipped to manage all the aspects of their children's educational needs when confronted by the seemingly immeasurable expertise of the teachers, administrators, related service providers, and other district personnel who control a child's educational program. Parents who request additional services for their children often run into difficulties obtaining what they believe their children need from school districts that face shortages of funds and personnel. Leiter and Krauss (2004), as part of a larger study, surveyed 278 parents who requested additional services for their children. They found that 80% of those parents had experienced problems in obtaining those services. According to the researchers, "The *combination* of requesting additional services and having problems was significantly related to parental dissatisfaction with their children's educational services" (p. 143). [Emphasis in the original.] They noted that the process of collaboration itself may be as important as the resulting programs and services. Again, honest

and open communication and collaboration with parents are key ingredients in developing successful plans for children with disabilities.

Problems arise—and can be avoided—at all levels of the planning and implementation processes. Unavoidable changes in personnel may require changes in a child's program, or may result in the way a program is implemented. A school needs to have in place a system whereby parents can be assured that their children are being served satisfactorily regardless of who is providing the services. In examining two California school districts that had substantially reduced the number of issues that proceeded to legal action, Mueller, Singer, and Draper (2008) uncovered three general areas that encompassed the original sources of problems between schools and families "lack of leadership; not keeping up with the law; and parents excluded" (p. 203). Many parents expressed displeasure with district directors: in one district because the director did not deal with parents' concerns fairly; in the other because the director was also a school principal and could not deal adequately with district complaints. The parents in both districts recognized that the schools were out of compliance with IDEA with the result that special education services were outdated and insufficient. Parents in both districts expressed dismay at being excluded by school personnel; they "did not feel listened to or honored as educational partners" (p. 206). Although the authors cautioned against generalizing from two small districts in a medium to high socioeconomic range, it is difficult not to see these complaints reflected in other school districts where parents are confronting similar problems obtaining appropriate education for their children with disabilities (Curtis, 2005; Kuriloff & Goldberg, 1997; Lake & Billingsley, 2000; Leiter & Krauss, 2004; Marchese, 2001; and Rickey, 2003). The districts that Mueller et al. studied made extensive changes in their systems and over time precluded many problems from proceeding to litigation. The authors commented that the

practices of the two school districts under study indicated that changes needed to be systemic and not piecemeal. In an earlier position paper, Mueller (1999) offered advice about building trust with parents in order to contribute to successful mediation and avoid litigation. Mueller recommended that schools should listen to parents' concerns and to "engage in systematic problem solving" (p. 92).

Congress recognized the need to avoid litigious confrontations if a student with a disability is to be served adequately and in a timely manner. The statute requires the school to provide for the resolution of complaints through formal mediation as well as the opportunity for interested parties to meet with a disinterested party. The law further requires that if mediation fails or is waived, schools must institute a resolutions session "with the parents and the relevant member or members of the IEP Team who have specific knowledge of the facts identified in the complaint" (§ 1415 (f) (1) (B) (i)). The intent of Congress seems clear that resolving conflicts short of litigation is the preferred approach.

Margolis (1998) offered eight lessons to avoid having conflicts escalate to due process hearings: the first was listening to parents, specifically listening to their concerns and fears. Schools need to be responsive to parents' needs in order for them to be equal partners in the education of their children. He recognized that treating parents as allies, and avoiding the due process contests, increased the probability that the team could reach a satisfactory resolution and maintain an amicable relationship. During an appeal regarding placement of a boy with Tourette's syndrome, Judge Bryan of the 9<sup>th</sup> Circuit Court of Appeals eloquently emphasized the importance of collaboration rather than contention in serving the needs of a child with a disability:

Working out an acceptable educational program must, in the end, be a cooperative effort between parents and school officials; the litigation process is simply too slow and too costly to deal adequately with the rapidly changing needs of children. In addition litigation tends to poison relationships, destroying channels for constructive dialogue that may have existed before the litigation began. This is particularly harmful here, since parents and school officials must—despite any bad feelings that develop between them—continue to work closely with one another. As this case demonstrates, when combat lines are firmly drawn, the child's interests are often damaged in the ensuing struggle (*Chyde v. Puyallup*, 1994, Footnote 5).

As with any search for common ground, cooperative rather than adversarial process will produce a more satisfactory result.

Despite the preference for mediated solutions, there is still a perceived distance between parents and schools that cannot always be bridged without dissention. Regardless of the intent of mediation to reach an agreeable solution, that solution may not be viewed as right or fair by parents who believe that in reality the playing field is not level. (As will be noted later, this impression was virtually reified by the Supreme Court decisions in *Schaffer v. Weast* and *Arlington v. Murphy.*) Parents are expected to be experts regarding their own children, but in addition to their understanding of their child's personality and individual needs, their knowledge is expected to encompass various aspects of the disability, the therapeutic and educational programs that would be effective, the advantages and disadvantages of differing placements, and their legal rights and safeguards. Is it reasonable to expect parents to be the repository of so much information? If, as one would hope, schools become increasingly sophisticated in their

understanding of pedagogy and appropriate educational programs for students with disabilities, the distance between parent and school experts becomes greater.

Blau (2007) suggested that the imbalance of power that renders mediation underutilized is inherent in IDEA itself. Although the statute promotes the role of parents as equal members of the planning team, it still leaves the decision making power in the hands of school personnel in whom it is supposed the expertise in pedagogy resides. Blau contended that IDEA provided parents with "little more power than was necessary to approve or disapprove the recommended services, veto power to refuse them, and a 'voice' to provide input in recommending alternative services; a voice, many felt, that was not often heard outside the due process protocol" (Sec. III, Para. 4). Parents who believe that they have limited control over the education of their children are not likely allies with those exerting ultimate control. Even the required dispute resolution sessions leave the decision-making power in the hands of school personnel. As parents continue through the educational system barriers accumulate and become more difficult to surmount. Blau identified a procedural hindrance to mediation as well. The "stay put" rule does not apply to mediations prior to due process complaints. If a parent wishes to protect the placement of her child, she would be compelled, therefore, to formally apply for a due process hearing, thus undertaking an adversarial position before mediation occurs.

Mediation is essentially a formal procedure usually initiated after a request for an impartial due process hearing. The need for mediation carries with it the implication that the process of collaborative planning has either broken down or was not in place to begin with.

Parents who enter into mediation are still faced with a phalanx of experts with access to further expertise, knowledge, and professional advice against whom they must argue. Marchese (2001) recognized the unequal footing of parents vis á vis a school district despite the intent of IDEA

to allow both sides to reach agreement without the protracted, legalistic procedures of due process hearings. Marchese pointed out that a parent represents "the prime agent" for assuring that the needs of her child are met. This places a heavy burden on a parent to understand the factors affecting her child's evaluation and placement. In addition the parent must be cognizant of her rights and the rights of her child while pursuing appropriate special educational services. According to Marchese,

This approach creates several difficulties. First, many parents lack the ability to be effective advocates for their children. At the IEP level, these parents may be unable to understand their children's placements, let alone articulate different ones. They may not be aware of the extent of their children's rights to FAPE or the procedural mechanisms to seek redress in case of disagreement. Second, the environment of the IEP process is heavily reliant on technical terminology to discuss the child's educational status and progress. Few parents are as conversant in the language as school personnel. Third, school personnel may not trust the input of parents who may be perceived as not being "objective' about the educational program for their children. (Sec. B, Para. 4).

With or without trust, however, there is always an imbalance of power at IEP meetings and even more so at formal mediations. Kuriloff and Goldberg (1997) recognized the risks involved in reaching agreements in mediation without judicial oversight. Because settlements are binding, parents need to be wary of signing an agreement reached during mediation. Parents may feel pressured to come to agreement and may naively succumb to subtle coercion from the district personnel. Kuriloff and Goldberg asserted that agreement does not necessarily equal fairness. Using data from 183 questionnaires sent to school officials and parents, they examined perceptions of fairness of mediations and their outcomes, and satisfaction with implementation

of the agreement. Their findings indicated only "mild satisfaction with mediation and perceived it only as a modestly fair procedure" (Sec. IV, Para. 3). One factor that significantly increased a parent's satisfaction and perception of fairness of the process and outcome was representation by an attorney. This reflects the opinion of other researchers that special education hearings are becoming increasingly legalistic (Zirkel, Karanxha, & D'Angelo, 2007). Kuriloff and Goldberg considered that because schools have the advice of many more experts, including attorneys, assuring that parents have representation of a lawyer may give them a chance to counter the imbalance of power and knowledge inherent in the process. They recognized that parents have such high stakes in the outcome of mediation because the procedures "evoke their basic protective instincts and the deep parent-child identification" (Sec. IV, Para. 13). It seems that recognizing parents' passions and abiding concerns for their children would improve the process from the very beginning so that the confrontations requiring mediations could be averted all together. Parents need to be able to depend on the professionalism of the teachers and administrators with whom they collaborate and have the right to expect appropriate and effective communication in the process of serving the needs of their children (Fish, 2008; Lake & Billingsley, 2000; Leiter & Krauss, 2004; Marchese, 2001; Margolis, 1999; Mueller, 2009; and Wanat, Helms, & Engvall, 1994).

In an analysis of decisions rendered in due process hearings in Iowa for a period of 12 years, Rickey (2003) discovered that issues of placement were most frequently the grounds for requesting due process. Most parents wanted their children placed in the least restrictive environment and specifically wanted them to be educated in their neighborhood school. Rickey analyzed the prevailing parties based on issues involved in the hearings and reported that school districts prevailed almost twice as often as parents. Although Rickey does not identify imbalance

of power as an influencing factor, it does not seem unlikely that school districts have greater resources and available expertise, both pedagogical and legal, and are more likely to prevail in educational disputes.

In an unpublished analysis of due process hearings in New Mexico for a period of two years, Duff (2006) recorded that 80% of due process hearings were appealed, thus prolonging the procedures prior to implementing a decision, sometimes for as much as a year. The most frequently cited complaint of parents was not being allowed full participation or not being adequately informed via prior written notice. Based on issues rather than on hearings, parents and districts prevailed almost evenly, either by favorable decisions solely or split decisions by the presiding officer. Although the trend of decisions did not favor either side, the need for due process hearings and subsequent appeals indicated that the collaboration between parents and school districts was not effective at the school level.

Recent Supreme Court decisions. Three recent decisions by the U. S. Supreme Court have a direct affect on the rights of parents in the process of educating their children with disabilities. As with any decision by the highest court, the ramifications are often uncertain and extensive. Yell, Ryan, Rozalski, and Katsiyannis (2009) reviewed the recent decisions and underscored the principle that regardless of the pro-school or pro-parent bent of the ruling, the Court consistently upheld the responsibility of a school district to provide every student with a disability a FAPE and in the process must "include parents in *all aspects* of their children's special education programming" [Emphasis added.] (p. 74). However, each of the three rulings will have an impact on the exercise of parental rights.

#### Schaffer v. Weast.

Summary and decision. The parents of Brian Schaffer, a student with a learning disability, believed that the placement offered by the Montgomery County Public School System (Maryland) could not provide the services that Brian required. They enrolled him in a private school and initiated a due process hearing in order to be compensated for their expenses. The administrative hearing resulted in a judgment against the Schaffers. According to the judge, each side presented an equally convincing case, but because the burden of proof belonged to the parents who challenged the placement, the judge decided that they had not met that burden. The U. S. District Court in Maryland disagreed with the allocation of the burden of proof on the parents and placed the burden on the district. The Fourth Circuit Court of Appeals reversed the decision and placed the burden of proof again on the parents. Brian's parents appealed to the U. S. Supreme Court.

The majority decision of the Supreme Court was that "the burden of persuasion in an administrative hearing of a challenge to an IEP was properly placed on the party—whether a child with a disability or a school district—seeking relief." Justice O'Connor in delivering the opinion of the Court cited the primary basis for this decision:

When we are determining the burden of proof under a statutory cause of action, the touchstone of our inquiry is, of course, the statute. The plain text of IDEA is silent on the allocation of the burden of persuasion....Decisions that place the entire burden of persuasion on the opposing party at the outset of a proceeding—as petitioners urge us to do here—are extremely rare. Absent some reason to believe that Congress intended otherwise, therefore, we will conclude that the burden of persuasion lies where it usually falls, upon the party seeking relief (*Schaffer v. Weast*, 2005, p. 51).

The Court further relied on aspects of IDEA to support their decision, stating that the statute deferred to the expertise of the school district in developing appropriate IEPs, that the statute included the "stay put" provision to protect the child, and that the perceived advantage of school districts was mitigated by the obligation placed on the districts to share information with the parents and to assure that they received notice of their procedural safeguards. In a statement concurring with the majority decision, Justice Stevens contended that "the court should presume that public school officials were properly performing their difficult responsibilities under this important statute" (*Schaffer v. Weast*, 2005, p. 63).

Reminding the Court that IDEA "casts an affirmative, beneficiary-specific obligation on providers of public education," Justice Ginsburg in her dissent stated that "the proponent of the IEP…is properly called upon to demonstrate its adequacy." Justice Ginsburg mentioned other factors that have been dealt with in this paper, including the imbalance of power and available resources between parents and school districts.

Justice Breyer dissented, claiming that because states were given the task of implementing IDEA, the decision regarding the burden of persuasion rightly belonged to the State.

Special educational issues involved in the decision. Prior to the Supreme Court's consideration of the case, the Harvard Law Review disagreed with the decision of the Fourth Circuit court, noting that the Court should have considered a "modified burden-shifting approach" (Disability Law, 2005, p. 1082) that would be more in line with the goals of IDEA and earlier precedents. It also noted that the procedural safeguards might not be sufficient protection of children with disabilities. In the subsequent Supreme Court ruling, Justice Ginsburg frequently referred to the dissent of Justice Luttig in the Fourth Circuit decision (Weast v. Schaffer, 2004).

The decision in *Schaffer v. Weast* places a heavy burden on parents who are up against a school district that has an abundance of experts, advisors, and attorneys on hand. Freed (2009) underscored this disparity: "Unlike school districts which retain taxpayer-financed lawyers and rely on the school's own employees to testify in due process hearing, parents of children with disabilities are often unable to afford legal counsel and expert witnesses" (p. 109). It is important to note here, that as will be discussed later in this paper, a subsequent Supreme Court decision put further strain on parents by denying them reimbursement for expert witness fees even if they prevail in their hearings. Freed, however, saw a way to reinstate parents' prerogatives, in reflection of Justice Breyer's dissent, he asserted that the negative effects on families can be assuaged by States in issuing regulations or statutes [as a number of states and the District of Columbia already have in place] that may justifiably assign the burden of persuasion to the school districts, thereby legally establishing procedures unaffected by Supreme Court ruling.

Dowling-Sendor (2006) examined the ruling and commented that it would not be likely that the decision would have a fundamental impact on the day-to-day workings of schools in developing individual programs for students with disabilities. However, he did note that it increased the likelihood of school districts' prevailing in due process hearings and saw "a subtle but real change in the balance between school districts and parents" (p.47). In a system in which the balance of power is already tilting toward school districts, the *Schaffer v. Weast* ruling increases the disadvantage of parents who confront a district with more 'firepower.' Conroy, Yell, and Katsiyannis (2008) pointed out that the decision did not diminish the responsibility of schools to meet the needs of students with disabilities and to abide by the procedural and substantive requirements of IDEA. They warn against school districts responding to the decision by

focusing on procedural compliance instead of implementing meaningful special education programs. (Conroy, et al., 2008; Freed, 2009).

Pendergast (2006) posited that the "misguided Supreme Court decision" (p. 879) could be countered by amendments to IDEA that would render the decision moot. Under the current decision, according to Pendergast, "the burden places no grave imposition on the schools, but it places the gravest on students and their families" (p. 888). Relying on impartial due process is a way to guard against school districts that are negligent in providing adequate services. Relieving them of the burden of persuasion shortchanges the parent's minimal control over their children's rights. Pendergast recommended "in the only clear hope of brightening a bleak landscape" (p.880) that Congress should amend IDEA to incorporate specific language to preserve its goal of equity in education.

## Arlington v. Murphy.

Summary and decision. The parents of Joseph Murphy sought to have the costs of a private school placement reimbursed by the Arlington Central School District Board of Education in New York. The parents prevailed in the District Court for the Southern District of New York. The school district appealed to the Court of Appeals for the Second Circuit where the district court's decision was affirmed. The Courts granted reimbursement to Joseph's parents for the costs of the educational consultant who assisted them in the lengthy legal process. The school district appealed the decision to the Supreme Court.

Once again the Supreme Court relied on the text of the statute on which to base its decision. Justice Alito delivered the opinion of the Court in which he cited the language of IDEA:

While authorizing the award of reasonable attorney's fees, the Act contains detailed provisions that are designed to ensure that such awards are indeed reasonable. The absence of any comparable provisions relating to expert witness fees strongly suggests that recovery of expert fees is not authorized (*Arlington v. Murphy*, 2006, p. 293).

The Court also considered interpretations of the spending clause of the U. S. Constitution [Art. I, § 8, cl. 1.] and considered that States who accepted federal funds do so voluntarily and should know the terms of the agreement unambiguously. By that reasoning, therefore, the Court concluded opinions based on information other than the statute itself were "plainly insufficient to provide clear notice regarding the scope of the conditions attached to the receipt of IDEA funds by the states."

In the dissenting opinion Justice Breyer, joined by Justices Stevens and Souter, cited the significance of a House Conference Report of Congressional intent in the initial enactment of the Handicapped Children's Act of 1986. The report clearly stated the meaning of reasonable costs includes "reasonable expenses and fees of expert witnesses...necessary for the preparation of a parent's or guardian's case" (H. Rep. No. 99-687, 1986). The Justice also pointed out to the Court that no Senator or Representative objected to the statement prior to voting approval of the report. He stated, "I can find no good reason for this Court to interpret the language of this statute as meaning the precise opposite of what Congress told us it intended" (*Arlington v. Murphy*, 2006, p. 313). Justice Breyer also claimed that to deprive parents of the right to recoup expenses of expert witnesses infringed on the student's right to an education that was both "appropriate and free." He also commented poignantly that the current linguistic approach of the Supreme Court "divorces law from life" (*Arlington v. Murphy*, 2006, p. 323).

Special education issues involved in the decision. Yell, Katsiyannis, Ryan, and McDuffie (2008) supported Justice Breyer's dissent. They recognized that expert witnesses are the only individuals permitted to provide opinions as testimony; thus, denying reimbursement of expert witness fees presents a significant barrier for parents, especially those who cannot afford to bear the costs.

Reed (2008) proposed an explanation of the conflict in the way statutes are interpreted.

The first, "classical intentionalism" recognizes that statutory language is imprecise and fallible and that interpretation of a statute requires looking into legislative history for "contextual interpretation." The second, "textualism" reads the language in a statute according to the conventional, or dictionary meaning of the words (pp.286-287). Reed claimed that in line with Justice Breyer's dissent, the Supreme Court erred in resorting to a textual reading of IDEA and ignoring Congressional intent and the ultimate purpose of the law. According to Justice Breyer, to view each statutory detail of a highly complex federal/state program simply through the lens of linguistic clarity rather than to assess its meanings in terms of basic legislative purpose, is to risk a set of judicial interpretations that can prevent the program, overall, from achieving its basic objectives or that might well reduce a program in its details to incoherence (*Arlington v. Murphy*, 2006, p. 318).

The decision in *Arlington v. Murphy*, according to Reed "impedes, rather than advances, the goals of IDEA by imposing a significant obstacle for low-income parents" (p. 295).

Reed (2008) further indicated that a particular area in which the opinions of experts are sorely needed is in instances of children with Autism Spectrum Disorder (ASD). ASD is so varied in its manifestations in children and so wide-ranging in effective interventions, that there are few school personnel who are able to assess students with ASD accurately and to propose programs that are suited to their distinct needs. The disorder is complex and inconsistent from

child to child. Expert advice is required for the school district as well. However, school districts have experts on hand, on the public payroll to offer expert opinions. Without the counsel of experts in the field, parents cannot effectively challenge the asserted expertise of school personnel who provide services and interventions.

### Winkelman v. Parma City School.

Summary and decision. Jacob Winkelman is a boy with ASD. His parents objected to an IEP presented by the Parma City School District in Ohio as being deficient and therefore denying their son FAPE. They requested a due process hearing; they did not prevail. After appealing for a State level review, they again did not prevail. The parents then requested a hearing in the District Court for the Northern District of Ohio. Once again the courts found for the school district. Still appealing the decision pro se, the Winkelmans' appealed to the 6th Circuit Court. Without hearing the facts of the case the Court dismissed the appeal unless the Winkelmans retained an attorney. The Winkelmans on behalf of themselves and their son appealed pro se to the Supreme Court. The Court declared that "The parents of a covered child under the Individuals with Disabilities Education Act...enjoy enforceable rights at the administrative stage, and it would be inconsistent to bar them from continuing to assert these rights in federal court." The Court reversed the judgment of the 6th Circuit and remanded the case. Because under IDEA parents have independent, enforceable rights, the Court reasoned that they are "entitled to prosecute IDEA claims on their own behalf."

Justice Kennedy in providing the opinion of the Court cited language directly from the statute.

IDEA defines one of its purposes a seeking 'to ensure that the rights of children with disabilities and parents of such children are protected' § 1400 (d)(1)(B). The word 'rights'

in the quoted language refers to the rights of parents as well as the rights of the child; otherwise the grammatical structure would make no sense....We find no reason to read into the plain language of the statute an implicit rejection of the notion that Congress would accord parents independent, enforceable rights concerning the education of their children. We instead interpret the statute's references to parents' rights to mean what they say: that IDEA includes provisions conveying rights to parents as well as to children (Winkelman v. Parma City School District, 2007, p. 529).

The Court once again resorted to textual rather than intentional analysis of the statute.

Special education issues involved in the decision. The changes in the Court's interpretive viewpoints have been explained as part of a legal cycle promulgated by Nathan Isaac a former professor of Business Law at Harvard Business School (Flaks, 2009). Flaks included his claim that "legal forms change in response to the changing needs of society" (p. 277), moving from codification of a principle in precise, text through a stage of interpretive rather than literal understandings of a statute, and eventually to the codification of revised principles in a new statute.

Flaks expressed concern that the decision to allow parents to pursue IDEA cases pro se, may conflate the rights of parents with distinguishable rights of the child. In reference to Justice Kennedy's reliance on grammatical structure, Flaks questioned if that stand might preclude the possibility that the rights of parents are not identical to those of the children. The Court left unexamined the issue of whether or not parents would be allowed to represent the rights of the child, pro se.

Steiner (2007) carried the concern for children's rights further in criticizing the Court's decision in *Winkelman v. Parma*. Steiner contended that the Court's decision "effectively allows

parents to litigate interests belonging to their children" (p. 117). Children also have been considered deserving of special protection as wards of the court. Steiner asserted that parents may compromise a child's best interests because of lack of legal knowledge and experience.

### Students' Rights

It is difficult to tease out of IDEA the rights of the student as distinct from those of the parents. The conflation of rights is underscored by the decision in *Winkelman v. Parma City School District* which allows parents to represent themselves *pro se* in federal courts because they have substantive rights in the statute. The question then remains, where do parental rights leave off and where do students' rights begin?

The issue of children's rights, especially children with disabilities, is complex. On the international stage, one must consider a number of conventions conceived and approved by the United Nations. The following section will consider a number of these documents and explore their relationship to the rights of children with disabilities in the United States.

The role of the United Nations. The United Nations has issued unequivocal statements about the rights of individuals, including the right to education. The *Universal Declaration of Human Rights* asserts that "all human beings are born free and equal in dignity and rights" (Article 1). Individual rights are further explicated in Article 6 which affords recognition to everyone everywhere as a person and Article 19 that affirms that "everyone has the right to freedom of opinion and expression." [Italics added.] How do we interpret "everyone"? Does it include children, or do the rights of parents supersede?

The United Nations has also produced the *Convention on the Rights of Persons with*Disabilities. This document makes specific references to children with disabilities and claims that "States Parties shall take all necessary measures to ensure the full enjoyment by children with

disabilities of all human rights and fundamental freedoms on an equal basis with other children" (Article 7). Article 7 of the Convention supports the rights of children with disabilities to "express their views and that their opinions be given due weight in accordance with their age and maturity." On July 24, 2009, President Obama signed this convention; in 2012 it was rejected by the Senate for ratification.

Another convention, which is more controversial in the U. S., is the UN *Convention on the Rights of the Child*, drafted in 1989. [There are only two nations that have not signed on to this Convention: Somalia and the United States.] This Convention echoes previous documents in considering the "best interests of the child" (Article 3) and in assuring to the "child who is capable of forming his or her own views the right to express those view freely" (Article 12).

The United Nations, while recognizing the value and importance of the family, has consistently and repeatedly supported the rights of the child. Stemming from the Declaration of Human Rights, the United Nations recognizes children as human beings first and therefore entitled to all the rights accorded to all human beings. The General Assembly again supported the rights of children to be listened to and asserted that "We must respect their right to express themselves and to participate in all matters affecting them" (A World Fit for Children, Declaration (I) (7)). In each case, these rights are granted to all children, including children with disabilities. A common theme that runs through these documents is the right to be respected as a person—and that this right extends to all children, including children with disabilities.

Freeman (2007) emphasized the importance and value of rights as "inclusive...universal, available to all members of the human race" (p. 7). Freeman further designated the "most fundamental of rights is the right to possess rights" (p. 8). Doek (2006) reaffirmed that children

deserved the respect accorded to human beings and that the "child is more than an object of care and protection" (p. 199).

**Resistance of the United States.** The United States is a signatory to the *Universal* Declaration of Human Rights. As mentioned above, under the direction of President Obama, the Ambassador to the United Nations has signed the Convention on the Rights of Persons with Disabilities; it was sent to the Senate and was not ratified. The sticking point seems to be the Convention on the Rights of the Child. This Convention was issued in 1989, but the United States (along with Somalia) has still not ratified the agreement. Opponents of the Convention present it as compromising American sovereignty and suggest that certain articles of the Convention are not congruent with the system of federalism in which issues of family and education typically fall within the domain of the states (Gregory, 2002; and Kilbourne, 1998). One such issue is the banning of corporal punishment. The prohibition against corporal punishment could effectively place limits on the role of parents in disciplining their children in order to protect the children's rights under this Convention (Hale, 2006). In the United States "any state may grant local school boards the option of permitting corporal punishment" (Gregory, p. 146). There is evidence that opposition to the Convention is grounded in conservative political philosophy that seeks to protect states' rights and the primacy of parental control over children (Kilbourne). Despite sometimes quite vocal opposition, there are indications that the U.S. may be more accepting of the precepts in the Convention on the Rights of the Child. Justice Kennedy, in delivering the majority opinion in Roper v. Simmons, a decision that banned the death penalty for juveniles under the age of 18, recognized international opinion against such penalties and made specific reference to Article 37 of the United Nations Convention on the Rights of the Child. Cheng (2008) stated that the Supreme Court has a history of interpreting "federal statutes consistently with

international law" (p. 286). According to Human Rights Watch (2009), "In 2009, the State Department initiated an interagency review of the CRC" (Para. 7). Perhaps if the United States ratifies the *Convention on the Rights of the Child*, we will see further compliance with the admirable intentions of the United Nations—and the rest of the world.

The right to education. The United Nations has consistently and frequently asserted that individuals have the right to education. This right is inextricably tied up with other human rights. The *Universal Declaration of Human Rights* specifically directs education to developing fully "the human personality and to the strengthening of respect for human rights and fundamental freedoms" (Article 26). Luckasson (2006) asserted that education is a means for individuals to "meaningfully exercise their human rights" (p. 13). According to Burke (2007) the right to education includes the right to develop a person's "intellectual rights with the aim of educating the whole person" (p. 338). Grover (2007) extended the description of education to include tolerance and claimed that the denial of "educational opportunities is a major vehicle for suppression of [marginalized groups]" (p. 59). Article 29 of the convention on the Rights of the Child delineates further directions in the education of children:

States Parties agree that the education of the child shall be directed to:

- (a) The development of the child's personality, talents and physical abilities to their fullest potential;
- (b) The development of respect for human rights and fundamental freedoms...;
- (c) The development of respect for the child's parents, his or her own cultural identity, language and values, for the national values of the country in which the child is living, the country from which he or she may originate, and for civilizations different from his own;

(d) The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of the sexes, and friendship among all peoples, ethnic, national, and religious groups and persons of indigenous origins."

This directive recognizes the value of children as human beings and goes well beyond the ordinary viewpoint of education as the "three Rs," and is geared toward developing individuals who are able to achieve their fullest potential in the world.

The right to education for children with disabilities. Again, the United Nations has agreed repeatedly that children with disabilities must have the same opportunities to education as are provided for all children. The various declarations and conventions also insist that children with disabilities receive the additional assistance they need in order to participate fully along with their peers. Equal opportunities for children with disabilities are specifically cited as both goals and policies of education programs. Lansdown (2009) in discussing the Convention on the Rights of the Child, cited education as an effective vehicle for confronting "the exclusion, poverty, marginalization, and stigma faced by children with disabilities" (p. 107). In A World Fit for Children, the General Assembly discussed accessibility, inclusion, and responsiveness to the needs of "children with learning needs and ...children with various forms of disabilities" (Sec. 40). The document further recommended that measures be adopted to ensure the elimination of discrimination for children with disabilities and to guarantee them equal access. The Convention on the Rights of Persons with Disabilities makes specific mention of children with disabilities and the responsibilities of the States Parties to provide "inclusive, quality, and free" education (Article 14). The most comprehensive document dealing with education of children with disabilities is the Salamanca Framework. The framework is rife with declarations of the necessity to provide education for all children in inclusive schooling. The framework also provides guidelines for

educational programs to provide for the special needs of students with disabilities within the context of inclusive schools at all levels.

How are these rights and recommendations reflected in American statutes and case law as they pertain to students with disabilities in the United States? The following section will examine these issues with emphasis on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA).

### The rights of children under IDEA

Free appropriate public education. In general terms, the most fundamental right afforded to children with disabilities in IDEA is the right to a free appropriate public education (FAPE) in the least restrictive environment (LRE). Congress explicated and expanded this right in establishing goals and setting policies to see that these rights were afforded to students. The findings include statements of policy for the nation of "ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities" (§ 1400 (c) (1)). The goals in this statement surpass the earlier decision in Board of Education v. Rowley that required that a child with a disability's individualized education program provide merely "educational benefit." The current IDEA statement is more in line with the Convention on the Rights of Persons with Disabilities that requires nations to ensure an education that helps persons with disabilities achieve development to "their fullest potential" (Article 14). IDEA reemphasizes the expansion of the Rowley criteria in the Purposes: the educational program must not only meet the educational needs of children with disabilities but also must "prepare them for further education, employment, and independent living" (§ 1400 (d) (1) (A)). The concept of preparing students for further education was included in the reauthorization of IDEA. It

recognizes the need to provide opportunities for children with disabilities to move beyond the limited expectations to which they have been held in the past.

Access to general education. Students with disabilities have the right "to the maximum extent appropriate" to be "educated with children who are not disabled" (§ 1402 (a) (5) (A)). The law also mandates that children with disabilities may not be removed from regular education classes unless there are compelling reasons to do so. Instructions regarding the Individual Education Program (IEP) reinforce this right by stating that the IEP must include goals that "enable the child to be involved in and make progress in the general education curriculum [Italics added]" (§ 1414 (d) (1) (A) (i) (II) (aa)). The IEP team must include a general education teacher. It should be noted that the IEP team should also include the child. However, the statute adds the limitation "whenever appropriate" (§ 1414 (d) (1) (B) (vii)). Lundy (2007) pointed out that listening to children is a model of good practice and that their perspectives should be "viewed as an integral part of school discourse rather than an attempt to undermine authority" (p. 934).

Non-discriminatory evaluation. Children have the right to an unbiased, complete evaluation. If parents do not consent, the local educational agency may pursue due process proceedings in order to conduct the evaluation. However, they may not initiate services without the informed consent of the parents. It would seem that in such cases, when an evaluation deems services are required and parents refuse, that the rights of the parents are in direct conflict with the rights of the child—a murky area at best. The law does consider, however, children who are considered wards of the state. If the child's parents cannot be located or if their parental rights have been taken away, the court may appoint an individual to represent the child's best interests and protect her right to an evaluation.

Inclusive Education. IDEA does not use the term inclusion; instead it speaks of the least restrictive environment. However, LRE is consistently described in the law as inclusion in general education as the first and least exclusionary placement for children with disabilities; therefore, I choose to use the terms synonymously. The United Nations' documents are unequivocal in their insistence on inclusive education. The Salamanca Framework (United Nations Educational and Cultural Organization, 1994) echoes and extends the mandates of IDEA. According to the Framework:

Inclusive schooling is the most effective means for building solidarity between children with special needs and their peers. Assignment of children to special schools—or special classes or sections within a school on a permanent basis—should be the exception, to be recommended only in those infrequent cases where it is clearly demonstrated that education in the regular classrooms is incapable of meeting a child's educational or *social* [Italics added] needs (p. 12).

In addition to the requirements mentioned above that students with disabilities be educated with their nondisabled peers, IDEA also links funding to compliance with its mandates for the least restrictive environment and disallows systems that distribute funds based on settings. IDEA delineates further its insistence that children remain in general education classes and

special classes, separate schooling, or other removal of children with disabilities from the regular education environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (§ 1412 (a) (5) (A)).

Kenworthy (2000) described segregated settings as the "twentieth century gulags" (p. 219) that are the result of the intolerance of adults who "by virtue of maturity and experience,

have a moral duty to listen to [children] and promote their right to be included and their acceptance" (p. 225).

Students with varying degrees of disability are routinely segregated from general education classes where teachers do not provide instruction that meets the different needs of all children. Often students with specific learning disabilities are singled out and placed in separate groups within the class or sent to separate classes. Ho (2004) blamed the use of a medical model of diagnosis of a disability that "assumes the defect and failure are in the child...rather than caused by poorly developed regular classroom practices" (p. 88). Weintraub (2005) warned against a return to the "traditional standard of sameness" (p. 99) if we continue to use standardized testing to segregate students whose educational achievements are not amenable to typical standardized tests. Schools need to be vigilant to ensure that students in special education are not shortchanged in the process of complying with the No Child Left Behind Act of 2001 (NCLB). It is still necessary that children with disabilities are afforded the rights and protections to which they are entitled under the law (McGrath, 2004).

Transition and transfer of rights. Students with disabilities are entitled to specific services related to transition to life after high school. At age 16 their IEPs must include "appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills and the transition services (including courses of study) needed to assist the child in reaching those goals" (§ 1414 (d) (1) (A) (i) (VIII) (aa-bb)).

A student must be advised no later than one year prior to the age of majority that rights will transfer to her once that age is reached. Unless a child is legally determined to be incompetent, the rights previously afforded to her parents devolve to her. However, under a

Special Rule, a child may be determined not to have the ability to provide informed consent regarding her educational program, in such cases the State can establish mechanisms to appoint parents or other individuals to protect the child's educational interests. (§1415 (m) (2)).

#### The Role of Teachers and Teacher Education

Knowledge of the law. Special education requirements to comply with the law are many and varied, including parental participation and the development of sound educational plans for students with disabilities. There is a substantial need for teachers, especially special education teachers, to be conversant with their legal responsibilities (Gullatt & Tollett, 1997; Painter, 2001; Weishaar, 1997; Werts, Mamlin & Pogoloff, 2002; Redfield, 2003; Schimmel & Militello, 2007; Yell, Shriner & Katsiyannis, 2006; and Zirkel & Vance, 2004). Researchers suggest that teachers ignore legal requirements at their peril. Gullatt and Tollett (1997) asserted that new teachers who "lack experience and judgment" (Educational Law and Teacher Education Programs, para.3) would have been well served by an educational law course during their preservice training. They recommended that schools of education include educational law courses at both the undergraduate and graduate levels that would include information, among other topics, about privacy of student records, Section 504, and special education law. Weishaar (1997) emphasized the expedience of avoiding due processs hearings or further litigation and asserted that teachers who were knowledgeable about the law and related court decisions would be better able to avoid such proceedings. Weishaar focused on issues of inclusion and offered suggestions to teachers in considering matters of placement and provision of supports and services that comply with IDEA and related case law. An essential element of a student's special education program is the IEP. In citing Bateman and Linden (1998), that "many IEPs are not educationally or legally correct" (Para. 1), Werts, Mamlin, and Pologoff (2002) recommended

that teachers be given adequate information about the history and context of special education law in order to facilitate IEP meetings and develop programs that comply with the legal requirements of IDEA. The Interstate New Teacher Assessment and Support Consortium (INTASC) (2001) also asserted that special education teachers need to know what is required by law to be included in the development of IEPs—both programs and documents. INTASC, in formulating model standards described further responsibilities of teachers. The consortium contended that both general and special educators understand "the underlying values and implications of disability legislation and special education policies and procedures" (p. 10). The consortium further maintained that special education teachers not only know the law and its influence on progress in special education history, but that they also serve as providers of information about legal obligations and policies.

The history of education in the United States has been significantly influenced by the legal system. *Brown v. Board of Education* (1954) is a striking example of the way that the course of education changed (though slowly) based on legal proceedings to protect the equal rights of students. Legislation as well as court decisions also decide the direction of education. Consider the overwhelming tasks facing schools trying to comply with No Child Left Behind; the sanctions associated with non-compliance override the professional wisdom of teachers and building administrators. IDEA though necessary and effective in protecting the rights of students with disabilities, is also replete with complex compliance issues that often derail the intent of individual programs. Redfield (2003) commented that the law might have been different "had educators written that first draft" (Sec. IV, para. 8). Redfield proposed collaboration between lawyers and teachers, especially in creating programs both for law students and education students in order to ensure that schools are able to understand the

implications of the law as it affects policies and procedures. Redfield recommended that teachers should be required to take at least one law course that offers them a wide enough range to be able to deal with the rights of students and their responsibilities to them.

Yell, Shriner and Katsiyannis (2006) listed as their *first* recommendation for special education teacher trainers that they "ensure that teachers and administrators understand the essence of the IDEA....which emphasizes the importance of meaningful programming by stressing the importance of the substantive requirements of the law" (p. 19). Their sentiments were echoed by Balch, Memory and Hofmeister (2008) who also pointed out that teachers are responsible for the success of their students and part of that responsibility is being "responsive to the legal context of teaching" (p. 5).

In 1983, Sametz described the deficiency of law education for teachers. Twenty-four years later, Schimmel and Militello (2007) recognized the same deficiency in teachers' legal literacy. They conducted a survey of teachers from 17 states and found that "over 75 percent of the 1,317 teachers surveyed had taken no course in school law and over 50 percent of respondents are uninformed or misinformed about teacher and student rights" (p. 262). They recommended yet again, as many had before them, that teacher certification programs should require coursework in education law for all preservice teachers.

Although there are serious criticisms of the role, procedures, and authority of the National Council for Accreditation of Teacher Education (NCATE) (Bullough, Clark, & Patterson, 2003; and Varenne, 2007), NCATE (2008) still determines the definitive standards for schools of teacher education. Despite their forceful influence on programs of teacher education, there is very little mention of familiarity with education law. There is no mention at all in the Council's vision statement, and there is no mention of the law in the target goals of Standard 1,

Candidate Knowledge, Skills and Professional Disposition. However, there is a passing reference in the supporting explanation: "[Teachers] understand and are able to apply knowledge related to the social, historical, and philosophical foundations of education, professional ethics, *law*, and policy"[emphasis added] (p. 22). In a succeeding section on program standards in a list of "what every special educator must know and be able to do, the following items appear: "Special educators understand the *legal* and ethical principles of *assessment*," and "Special educators are viewed as specialists ...[and] a resource in understanding *laws*, policies, and effective practice" [Emphasis added.] (pp. 73-74). Other than those few references, there are no other indications that NCATE considers knowledge of the law as an essential element of teacher preparation.

INTASC (2001) listed as one of its core requirements under School and Community

Involvement: "The teacher understands and implements laws related to students' rights and
teacher responsibilities" (Sec. 10.13). [In a parenthetical list of examples, INTASC unfortunately
used the term "handicapped" students rather that the more appropriate person-first language.]

In a list of over 350 core requirements only one makes reference to the law.

The Council for Exceptional Children (2004) in its list of content standards for beginning teachers in special education included three distinct references to the law. In its first standard, Foundations, CEC asserted that "special educators understand the field as a evolving and changing discipline based... on relevant laws and policies" (p. 22). CEC later asserted in the 8th standard that special educators needed to be familiar with the legal requirements for assessment, eligibility, and placement of students with disabilities. In the 10th standard CEC stated that special education teachers serve as resources for information about and interpretation of laws relating to students with disabilities. A major statement in the CEC code of ethics for special education teachers stated "Special education professionals seek to uphold and improve

where necessary the laws, regulations, and policies governing the delivery of special education and related services and the practice of their profession" (Code of Ethics, Principle G).

Without reference to specific case law or statutes, the New Mexico Administrative Code, lists among the first competencies for beginning special education teachers that they are able to "explain and discuss current and historical state and national rules and regulations relating to special education practice;…the procedural safeguards relating to educational services;…and state and federal mandates for students with disabilities" (§ 6.61.6.10 A. (1) (b-d).

It seems that despite the frequent recommendations that teacher education—and specifically in the area of special education—include thorough understanding of education law, the institutions that inform schools of education and establish program requirements do not incorporate legal literacy into prerequisites for beginning teachers.

Working collaboratively with families and teacher preparation. Parents have vested interest and a meaningful role in determining special education programs for their children with disabilities. To establish effective and meaningful programs parents should be part of the proceedings from the beginning. Their knowledge of their children is extensive and will aid school personnel in meeting the needs of the children with disabilities. Too often schools devalue parental assessments of their children in favor of assessments by so-called experts. Such behavior denies the inherent expertise of parents who, regardless of the degree of others' expertise, know their individual children better than anyone else. Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004) as part of their study of family members and professionals included a poignant quote from a father of a child with a disability: "The first thing is to listen to us...because we know our kids better than anybody....I think some of these people have preconceived notions about everything....so if I tried to say, to tell [the professionals]

something, it'd be LISTEN TO ME" (p. 175). Parents see their children in different settings and under different circumstances that are not available to teachers and administrators. Their knowledge is invaluable to a team in establishing meaningful special education services for children with disabilities. Even without the directives in the statute and succeeding case law, common sense alone would call for collaborating with parents. Teacher education that promotes a collaborative relationship with families can give beginning teachers insight into the process as well as defense against what might be questionable veteran advice.

Schools of education address the inclusion of parents in different ways, from no documented topics to inclusion of units within coursework to separate programs that immerse preservice teachers in understanding families. There is little distinction in the literature between family involvement in special education and general education. Discussions of parents of children with disabilities are often subsumed under the topic of parent involvement in general.

Significance of family involvement. The relationship between teachers and parents has been described in varying terms and with a variety of underpinnings. Collaboration between schools and families is referred to in the literature as parent involvement (Almeida, 1978; Chavkin & William, 1998; Greenwood & Hickman, 1991; Hoover-Dempsey, Walker, Jones, & Reed, 2002; McBride, 1991; and Young & Hite, 1994), family involvement (Baum & Swick, 2008; Giallourakis, Pretti-Frontczak, & Cook, 2005; and Shartrand, Weiss, Kreider, & Lopez, 1997), family and professional partnerships (Blue-Banning, et al., 2008; and Summers, Hofman, Marquis, Turnbull, Poston, & Nelson, 2005), school, family, and community partnerships (Epstein & Sanders, 2006), family/school collaboration (Katz & Bauch, 1999), family/school partnerships (Knight & Wadsworth, 1999), Family-Centered Program (Murphy, Lee, Turnbull, & Turbiville, 1995), teacher-family partnerships (Ratcliff & Hunt, 2009), and teacher and parent

involvement (Tichenor, 1997). Although the terminology differs, the basic premise is similar: teachers have an obligation to include parents and families as equal partners in their children's education. Murphy (1995) stated that "collaboration means that professionals learn from families as well as instruct them. When collaboration is a major component of family-professional interaction, such interactions are more likely to be substantive, rather than just superficial" (p. 27).

There is overwhelming support for the efficacy and importance of including parents as partners in the education of their children (Baum & Swick, 2008; Blue-Banning, Summers et al., 2004; Chavkin & Williams, 1998; Dardig, 2005; Epstein & Sanders, 2006; Forlin & Hopewell, 2006; Greenwood & Hickman, 1991; Hoover-Dempsey et al., 2002; Knight & Wadsworth, 1991; Ratcliff & Hunt, 2009; Shartrand et al., 1997; Spann, Kohler, & Soenksen, 2003; and Stoner, Bock, Thompson, Angell, Heyl, & Crowley, 2005). Forlin and Hopewell maintained that meaningful collaboration "has the potential to result in an empowerment model that will enable parents and teachers each to bring a different range of expertise, knowledge, understandings and competence that may truly enhance the further development of inclusive and democratic school communities" (p. 60). As in instances dealing with issues of law and pedagogy, parents are at an initial disadvantage when confronted by a team of experts, namely, teachers, administrators, related service providers, counselors, and other school personnel. Teachers, who are the common link between families and schools, need to be aware of their role in providing meaningful ways to include parents in the educational decisions and plans for their children. Baum and Swick (2008) claimed that "teachers need to see families as meaningful contributors to their child's education, whose knowledge, opinions, and concerns are a valuable and critical component of the educational process" (p. 580). Special education teachers should be in the

vanguard of advocacy for the children in their care and their families. The need for family involvement is especially acute for families of students with disabilities (Blue-Banning, et al., 2004; Knight & Wadsworth, 1991; Murphy, et al., 1995; Ratcliff & Hunt, 2003; Spann, et al., 2003; Stoner, et al., 2005; Van Haren & Fiedler, 2008; and Yoshida, Fenton, Kaufman, & Maxwell, 1994). In order to serve students and families well, teachers need to be aware of multiple aspects of a family's life, including the extended family where appropriate.

Perspectives of families. Parents have a vested interest, not only in the education of their children, but also in the preparation of teachers who are willing to collaborate effectively with families to ensure that children receive the educational and/or special educational services that they need and deserve. Murphy (1995) considered that family-centered practices should attend to families' points of view and include families in making decisions about the student.

Often, though parents expressed satisfaction with the process, further inquiry indicated that their role had essentially been passive (Goldstein, Strickland, Turnbull, & Curry, 1980; Lynch & Stein, 1982; Murphy et al., 1995; Spann et al., 2003; Stoner et al., 2005; Summers et al., 2005; and Yoshida et al., 1978). Summers et al. (2005) developed a rating scale citing 18 characteristics of teachers and other service providers in special education that families found led to successful "child-focused relationships." In using the instrument, parents would be asked to rate the following behaviors:

Your service providers...(1) Help you gain skills or information to get what your child needs; (2) Have the skills to help your child succeed; (3) Provide services that meet the individual needs of you child; (4) Speak up for your child's best interests when working with other service providers; (5) Let you know about the good things your child does; (6) Treat your child with dignity; (7) Build on your child's strengths; (8) Value opinions

about your child's needs; (9) Keep your child safe when your child is in their care; (10) Are available when you need them; (11) Are honest, even when they have bad news; (12) Use words that you understand; (13) Protect your family's privacy; (14) Show respect for your family's values and beliefs; (15) Listen without judging your child or family; (16) Are people that I can depend on and trust; (17) Pay attention to what you have to say; and (18) Are friendly (pp. 75-76).

This list presents a virtual summary of the expectations of parents as they are represented in the literature. It is apparent that parents' requests are reasonable and center on the well-being of their children. Teachers, especially special education teachers, have a professional as well as ethical responsibility to their students and their parents to recognize the importance of family relationships and not to allow their personal attitudes to obstruct potentially powerful collaborative efforts in developing successful educational programs (Baum & Swick, 2008; Ratcliff & Hunt, 2009; Shartrand et al., 1997; and Yoshida et al., 1978). Parents are concerned about the welfare of their children and expect teachers to understand and share in that concern. Teacher preparation programs need to find ways to instill in beginning teachers that parents are not ancillary to the education of students but integral to their success. Blue-Banning et al. (2004), in presenting the results of their study, summarized a philosophy that should guide teachers and those who instruct teachers. [The results] "underscore the point that common sense and ordinary human decency are at the heart of positive partnerships between families and professionals serving children with disabilities" (p. 181).

**Perspectives of preservice and beginning teachers.** In general, both undergraduate and graduate students in teacher education programs agree with parents about the importance of developing and maintaining good working relationships with families of their students, especially

families of students with disabilities, and recognized the need for training in that area (Forlin & Hopewell, 2006; Foster & Loven, 1992, Katz & Bauch, 1999; McBride, 1991; and Murray & Mandell, 2004). Students surveyed in Katz (1999) reported that a one-semester course was not enough to prepare them, and preferred "a more systematic and integrated approach" (p. 67). Foster's (1992) study of 120 teacher education majors also indicated that students desired a more systematic approach in learning to work with parents. Students in many special education teacher programs often have "only very limited direct contact with people with disabilities in the community" (Forlin & Hopewell, 2006, p. 56). Often preservice teachers are fearful of encounters with parents because they do not believe that they have the necessary communication skills to be able to develop a collaborative relationship. Adequate preparation as part of their education program could alleviate those fears and avoid developing "negative attitudes and feelings of frustration" (McBride, 1991, p. 58). Preservice teachers in both general and special education programs echoed researchers' and parents' recommendations that they have direct contact with families during their training (Katz & Bauch, 1999 and Tichenor, 1997). Preservice teachers found that even programs that included curriculum on parent involvement did not prepare them adequately for their work with students and their parents (Young, 1994). Teacher preparation programs should be expected to recognize the inadequacies and inconsistencies in programs that prevent preservice and beginning teachers from having the knowledge and skills they need to foster successful family-professional partnerships.

# Perspectives of administrators and faculty in teacher education programs.

Although few teacher preparation programs provide extensive training in parent/school collaboration, faculty and administrators agree that it is essential that beginning teachers have coursework and practical experience in developing parental involvement (Chavkin & Williams,

1998; Epstein & Sanders, 2006; Flanigan, 2007; and Knight & Wadsworth, 1991). Chavkin and Williams, in a frequently cited study, asserted, "An overwhelming majority of parents, superintendents, school board presidents, state education agency officials and teacher educators concurred on the need for teacher training for working with parents" (p. 87). Knight and Wadsworth (1999) reviewing their earlier study of 101 directors of special education teacher preparation programs, recognized that too few hours were spent on the topic and that the topic was distributed within "a hodgepodge of generic courses" (p. 24). Murphy et al. (1995) pointed out "an implementation gap between what is valued and what is practiced" (p. 24). Offerings in teacher education programs varied from no training at all to content covered in other courses to one or more courses devoted to the topic (Chavkin & Williams, 1998; Epstein & Sanders, 2006; and Young & Hite, 1994). Epstein and Sanders in a survey of 161 deans and department chairs in teacher education programs reported that these leaders believed that their current offerings were not adequate to meet the needs of beginning teachers in working successfully with families. Somehow there is a serious disconnect between what teacher educators, teacher education students and parents declare as essential and what is actually being offered in teacher training programs.

Implications for teacher preparation programs. Many researchers recognized the need for teacher education programs to expand their offerings in order to prepare teachers entering the profession for collaboration with families and school communities (Baum & Swick, 2008; Ratcliff & Hunt, 2009; and Van Haren & Fiedler, 2008). Ratcliff and Hunt recognized that lack of teacher preparation is "one of the most frequently mentioned barriers to promoting teacher-family involvement" (p. 499). Shartrand et al. (1997) pointed out that very few state departments of education, which exert control over the course requirements for licensing

potential teachers, included preparation in the area of parental involvement in their certification requirements. Baum and Swick, emphasizing the importance of preparing teachers to work with families, and recognizing the need for increased efforts on the part of teacher preparation programs, advised, "Teacher educators must critically examine their program's content to ensure that preservice teachers are adequately involved in studying family dynamics, as well as the various dimensions of a teacher's work with parents" (p. 582). Teacher educators need to reevaluate the programs offered to preservice teachers, especially in special education where collaboration can be critical to a child's success. Shartrand et al. (1997) suggested that incorporating family involvement programs at the preservice level would have the most significant impact on the greatest number of beginning teachers who would be able, then, to "significantly raise the quality of home-school partnerships" (p. 14). Those responsible for teacher education may need to look beyond state and accreditation requirements in preparing teachers to face the reality of the schools and communities in which beginning teachers must work.

Many national organizations have weighed in on issues of parental involvement in schools. The National PTA (2000) issued the *PTA National Standards for Family-School Partnerships:*An Implementation Guide. The guide contains valuable information gleaned from a national survey as well as recommendations and practical advice to assist parents in assuring that their schools meet standards for family-school partnerships. The six standards can be incorporated into teacher preparation programs: (1) Welcoming all families into the school community; (2)

Communicating effectively; (3) Supporting student success; (4) Speaking up for every child; (5)

Sharing power; and (6) Collaborating with community (p. 6).

The National Board for Professional Teaching Standards (NBPTS) has, in many instances, become a benchmark for evaluating teachers' skills, knowledge and practice. NBPTS includes explicit standards for parent involvement in each of its certification areas. For example, in Standard XVI of the Adolescence and Young Adulthood/English Language Arts section there is an extensive description of what "accomplished teachers" demonstrate in family and community involvement:

Accomplished English language arts teachers value and respect the roles of families, caregivers, and communities as critical influences on students....They recognize that schools can benefit from the varied cultural, linguistic, social and educational experiences that shape students' lives and responses to schooling, so the work with families, caregivers, and communities to take advantage of these sources of knowledge. (p. 77)

The requirements are even more extensive and explicit in standards for certification for exceptional needs specialists. Standard XII: Family Partnerships, delineates teachers' responsibilities in collaborating with parents:

[Accomplished teachers] clearly signal through word and deed the importance of families as partners with the school, striving to keep lines of communication open by creating an ongoing dialogue and seeking opportunities to involve families in the school and to involve themselves in the children's home and community.(p 67)

The preamble to INTASC's model standards includes the belief that professional teachers are responsible for "connecting" to parents and using community resources. Principle #3 proposes that knowledge, disposition, and performance of teachers include understanding of individual students' family, community and cultural norms. Principle #10 requires that the "teacher

establishes respectful and productive relationships with parents and guardians from diverse home and community situations" (p. 34).

#### Voices of Parents and Students

Ferguson (2009) studied documents from the eugenics movement in the early 20<sup>th</sup> century. He found among the documents from the Fairview Training Center in Oregon the radical underpinnings of the fanatical dominance of authority figures over the lives of families with disabilities. He pointed out that individuals with disabilities were institutionalized "to prevent the family from damaging society...[and to alleviate] the perceived fear...that the strength of the American culture was being dangerously diluted by the proliferation of the incompetent, the immoral, and the unproductive" (p. 54). Parents then as now wanted what was best for their children but were often rendered powerless by the machinations of those invested with power.

Parents' voices. Often the disparity in power is expressed in equivocal ways. Access to information and knowledge is one potential barrier to successful collaboration (Al-Hassan & Gardner, 2002; Crozier, 1999; Fish, 2006; Garriott et al., 2000; Johnson et al., 2002; Kozleski et al., 2008; O'Connor, 2001; Smerkar & Cohen-Vogel, 2001; and Valle & Aponte, 2002). Fish pointed out that although parents want to be involved in discussions, they find that they cannot match the expertise of teachers and other service providers. Smerkar and Cohen-Vogel, in their analysis of in-depth interviews with parents, concluded that patterns of communication were circumscribed by parents' perceptions of school officials' knowledge and expertise. They cited one parent of a special education student whose words evoke the futility of trying to exert influence. "I used to go to a lot of my son's IEP meetings. I would be the only one there who wouldn't have too much to say because the teacher, the principal, the psychologist, and whoever else would all be talking" (p. 93).

Besides knowledge imbalances is the correlated exclusionary use of language. Special education is fraught with acronyms and technical jargon that are confusing even to some practitioners and seem to be designed to obfuscate rather than clarify. Parents are often excluded from discourse by not being privy to the private language of teachers and other school professionals (Al-Hassan & Gardner, 2002; Harry et al., 1995; Hess, Molina, & Kozleski, 2006; Johnson et al., 2002; Lovitt & Cushing, 1999; Smerkar & Cohen-Vogel, 2001; and Soodak & Erwin, 1995). Technical terminology or what Valle and Aponte (2002) term insider language, permeates discussions and engulfs documents, especially those documents intended to inform parents: procedural safeguards and the IEP itself. Smerkar and Cohen-Vogel pointed out how the proliferation of such language could "foster and perpetuate feelings of distrust, distance, and disillusionment among parents" (p. 93). The IEP is the cornerstone of continuing educational services with students with disabilities, but often the contents of the document are indecipherable to anyone except educational professionals. Hess et al. cited a parent in a focus group who was frustrated by the lack of recognition of her assessment of her own child. "It was really difficult for me to sit through IEP meetings and different people would start talking gibberish....I would take that paper home, and I'd look at it and I'd be thinking, 'what in the world just happened?" (p. 153). Soodak and Erwin concluded from interviews with mothers of children with disabilities that parents were alienated by the school's use of impenetrable language. They also asserted that professional jargon "served to handicap the parent during discussions and ultimately limited their participation in the decision-making process" (p. 70).

There are mixed accounts in the literature about parents' perceptions of their role in the education of their children, in both general and special education. Often studies produced contradictory information in which parents expressed satisfaction with the special education

process and yet talked about the difficulty of finding out about and securing services for their children. Parents in Harry et al. (1995) reported that the "welcoming and open atmosphere diminished" (p. 369) when their children moved from pre-school to first grade. This trend of increasing inaccessibility of teachers continued throughout the three years' duration of the study. Ainge, Colvin, and Baker (1998), in a survey of students with intellectual disability, found discrepancies between individual and group data and suggested that survey information may not provide valid generalizations that would be useful in making predictions about needs of individual students. In a national survey of 510 parents of children with special needs, Johnson et al. (2002) reported that although a majority of parents praised schools and teachers,

Nearly a quarter give their child's special education teachers low marks on "skill and quality" and a substantial 38% say their child could be doing better in school if he or she had better teachers....More that 4 in 10 of high school parents also say that their child's special education program is failing or needs improvement when it comes to preparing them for life in the real world after high school (p. 24).

Parents who expressed dissatisfaction with their schools also cautioned parents to avoid getting on the wrong side of educators who are still responsible for their children's education. The parents in Soodak and Angell (1995) supported this admonition; they admitted that even after acquiring general education placement for their children with assistance from forces outside the school, they "continued to feel threatened by school administrators" (p. 272). These responses reflect the imbalance of power between parents and vast school bureaucracies.

**Parents' involvement in school activities.** Parents are willing to be involved in school activities as well as to be involved in individual planning. By taking part in the day-to-day happenings, parents believe that they can become a functional part of school decision-making.

However, the expressed desire to include parents is often illusory. Garriott *et al.* (2000) found that 27% of the parents they surveyed expressed extreme dissatisfaction with their children's special education program. According to Garriott *et al.* 

[Parents] felt devalued, disrespected, and ostracized from the planning process. Being placed in this subservient position seemed to create an unnatural dynamic in the parent/professional interaction that fostered submissive, dependent behavior on the part of the parent and dominant, authoritarian behavior on the part of the educator (Discussion para. 5).

Yanok and DeRubertis (1989) questioned over 1700 parents and found that "only a small portion had been contacted" (p. 196) to request their participation in school functions. Halsey (2005) reported that although teachers claimed to welcome parent involvement, parents perceived that there was no sincere invitation to be involved in their children's classrooms. In O'Connor (2001) one parent who volunteered regularly at her child's school still recognized the relative insignificance of her opinion to school officials:

Despite the 'wonderful contact' with the teachers she had as a volunteer, Caroline [parent] believed that her views and the views of other parents and community members had been disregarded when they attempted to be involved in important decisions about their children's school (p. 183).

In other studies parents believed that the schools invited their involvement as supporters of their students' education at home, by offering encouragement, checking and responding to school-home communication (which was often negative in nature) and helping their children with homework (Bennett, 2007; Crozier 1999; Halsey, 2005; McKay et al., 2003; Munk, Bursuck,

Epstein, Nelson, & Polloway, 2001; Smrekar & Cohen-Vogel, 2001; Stoner & Angell, 2006; and Yanok & DeRubertis, 1989).

Parents' participation in decision-making. Many parents, especially parents of children with disabilities, maintained that their ability to have significant influence on decisions regarding their children's educational plans was thwarted by intrinsic elements of the process, including attitudes, knowledge, bureaucracy, and perceived fiscal constraints. Stoner and Angell (2006) commented that the intent of IDEA is often muddied by the complexities of the process of implementing the evaluation and planning procedures. In Pruitt, Wandry, and Hollums (1998), parents asserted that if teachers knew the families better they would be better able to incorporate their knowledge and understanding into the individual plans for their children. Kozleski et al. (2008) reported that "School personnel failed to make the rules and process transparent....In subordinating the role of families to the work of researchers and practitioners, families' judgments, observations, and perspectives are also subordinated to professional knowledge building and judgment" (p. 32). Parents' unique knowledge of their children is elbowed out of the way to permit the "expert" knowledge of school personnel to take precedence; parents' voices are effectively silenced.

Parents who attempted to take an active role in decisions and planning for their children often focused on the importance of mutual respect and trust—both of which were frequently absent from interactions with school officials. Smerkar and Cohen-Vogel (2001) indicated that inequitable exchanges between schools and parents engender distrust. Stoner and Angell (2006) recognized that trust was a theme in their research, that parents' trusted school personnel conditionally, if at all. Stoner and Angell warned that "the cost of repairing trust is much higher than preventing its loss" (p. 186). Parents in Fish (2006) desired school districts to be *less deceitful* 

[emphasis added] in their meetings with parents. Pruitt *et al.* (1998) cited parents who desired to be treated humanely when talking about their children; who wanted to be treated with honesty and dignity. Pruitt included the words of a father of a 16 year old that are both sensible and poignant:

Listen [emphasis added] to what parents are saying. The parents really do know what's best for their children sometimes. People who are teachers and have no special ed kids of their own have no idea what we're going through (Results para. 6).

His voice, given expression in the interview study, is one that should be heard by every teacher who works with children with disabilities. Parents have a level of knowledge about their children that teachers cannot approach. Soodak and Erwin (1995) stressed that parents' knowledge of their children is as important as the perceived expert knowledge of educators. Choutka (1999) did not play a role in selecting educational objectives for her son who has autism and discovered after a functional behavior assessment that the drill that the educators had insisted on was increasing his self-injurious behavior. In remarking on the teacher's persistent request that her son "Touch green," Choutka lamented, "A functional assessment revealed that my son injured himself to escape the drill...for a skill that will not improve his life in any way that I can measure" (pp. 215-216). It is not difficult to imagine that his behavior could have been avoided if the professionals had listened to the boy's mother first—before planning interventions.

The IEP. Participation in the IEP meeting should be the occasion for parents' voices not only to be heard but also to be valued. In some cases, parents voices are not heard at all because the IEP document has been written before the meeting and their unique knowledge of their child has been omitted (Garriott et al., 2000). IDEA designates parents as members with equal participation on the team. However, as Soodak and Erwin (1995) reported, "Interestingly,

although the IEP meeting was initially established to provide a forum for parental involvement, it was at this meeting that many parents felt most alienated and ridiculed" (p. 273). Fish (2008) in a survey of 51 parents of students in special education reported that the majority of parents surveyed rated their overall IEP experiences as positive. However in an earlier (2006) interview study, Fish reported that all the parents interviewed stated their experiences had been negative. Why were the results so different over the course of two years? The answer may lie in two aspects of the research methods. In the 2008 study, results are less detailed and do not incorporate parent voice directly. In addition the parents included in the survey were all in middle and upper middle socioeconomic brackets. This sample population matches the typical teacher population and may account for the impression of favorable treatment. The 2006 study used interviews and revealed parents' opinions directly rather than as brief responses to a generalized survey. It was in this study that parents referred to deceitful practices of school districts, a topic that survey would not address. Does it seem reasonable, then, to assume that when parents' voices are heard, their reactions to IEP meetings are more revealing?

The parents in Fish (2006) reported that they had been treated negatively "at one time or another" by school personnel and that they were treated with more respect "when an advocate attended IEP meetings" (pp. 60-61). The parents in Stoner and Angell (2006) also reported using outside consultants to enhance their influence in IEP meetings.

Parents in general wanted IEP meetings to include them as equal partners in the enterprise, in which the conferences were "more of a democratic process where parents felt they were equal contributors" (Fish, 2006, p. 63). Stoner and Angell (2006) reported that parents prepared for upcoming IEP meetings to help them maintain focus on their goals for their children, and to help them, according to Lovitt and Cushing (1999), make teachers aware of the

"unique" needs of their children. However, many parents found that the eventual goals lacked individualization and were couched in language that was difficult to understand. Choutka (1999) pointed out that for many children with autism, the same goals reappear on their IEPs year after year. Pruitt et al. (1998) quoted the mother of an 8-year-old who asked of teachers:

Just be more helpful at IEP meetings and stuff. A lot of us parents...know what our kids are entitled to. It would be nice if teachers would help us fight to get our kids what they need and what they deserve (Results para. 39).

Least restrictive environment. Parents, according to Harry et al. (1995) originally accepted special education classes as an opportunity for their children to "catch up," but became disillusioned when they recognized that their children were placed in a program that was not socially appropriate and that isolated their children from the general education population. Parents in Kasari, Freeman, Bauminger, and Alkin (1999) cited inclusion as the "ideal" choice with the stipulation that additional services were provided [as required by IDEA]. In the focus groups in Hess et al. (2006), parents did not even consider inclusion a placement, "instead they defined it broadly as a 'sense of place' where their child belongs [emphasis added]" (p. 151). The theme of belonging recurred frequently among parents and was cited as a key feature of a "responsive school environment" (p.154). Belonging is a major component of the Circle of Courage, a framework for encouraging children to thrive in their society and live up to their potential, as described by Brendtro, Brokenleg, and Vanbockern (1990). The mothers in Soodak and Erwin (1995) also rejected segregated education because they "felt that 'separate' implied inferior...segregated education denotes exclusion and degradation which is the antithesis of what they want for their children—a sense of belonging" (pp. 266-267).

Students' voices. Students, it seems, have even less chance of being heard. At least parents, as adults, can meet school personnel on some sort of level playing field. Students, on the other hand, have been relegated to an even more submissive role. They are expected to be deferential to the adults who plan, implement, and supervise their education on a daily basis. Teachers are unquestionably in control and can determine a child's fate from day to day. Sadly, students in Medina and Luna (2004) referred to their special education classes as "jail" and "hell," both terms preclude any opportunity for students to assert themselves or to influence their condition. Reid and Button (1995) called students with disabilities the "forgotten element in the educational equation" (p. 607). Like the students in the Medina and Luna study, they felt trapped in an oppressive system that disallowed their voice. It seems illogical, but most teachers do not consider that students who do not appear to be learning may be able to tell them why they are failing. Teachers who try to be helpful offer strategies and advice, but rarely ask students for their input into their own learning. Curtin and Clarke (2005), based on research with students with disabilities, stated that "Listening to what young people with disabilities have to say about their education experiences is one way in which to determine how best to support their needs" (p. 199) Students, even more than parents, are often defenseless against the institutional power of schools. They often view the actions that educators take to help them as punishments. One student in an interview discussed his referral to a psychologist and perceived it

as an expression of the power the school had over him and means by which it was enforcing its view of the world on his life....He had no control over the issues that had been identified as important nor over the decisions that were being taken about his future (Ainge et al., p. 126).

Wearmouth (1999) presented a narrative of a man whose life was also virtually predetermined by the choices that were made for him in his education and that served to segregate him from "normal" society. When we allow powerful institutions ultimately to restrict children's choices, we are also restricting their options for full participation in life.

*Traditional school structure.* The intrinsic, competitive and comparative standards imposed by the traditional school structure are often the proximate cause of school failure for all students but more frequently and more prominently for student with disabilities (Armstrong, Dolinski, & Wrapson, 1999; Broer, Doyle, & Giangreco, 2005; Farrell, Peguero, Lindsey, & White, 1998; Fitch, 2003; and Reid & Button, 1995). Poplin (1995) asserted that students did not complain about schools being too difficult, but there were seemingly countless mentions of school being too boring. Students considered at risk for dropping out who found themselves in the same educational situation year after year, according to Farrell et al., became bored and "to expect students who have been judged inadequate for 10, 11, and 12 years to submit eagerly to yet another judgmental situation [inherent in a grading system] without a visible payoff is folly" (p. 500). Grades function as a scale of comparison among students both in general and special education. When students with disabilities are included in traditionalist general education classes, where Broer et al. described the practice as "hosting [emphasis added] rather than teaching students" (p. 427), the variation in grades can encourage a negative impression of students who struggle with non-differentiated assignments and thereby earn lower grades consistently. Rosenholtz and Simpson (1984) discussed how inequality is sustained by a system that assesses a "narrow range of allowable performances" (p. 37). They also discussed grades as "capable of reducing relatively complex performances to a single dimension....And grades increase the legitimacy of invidious, stratified comparisons. The policy of assigning grades forces both

teachers and students to attend to information structured to be inherently stratifying" (p. 39). Rosenholtz and Simpson presented an overview of the differences between traditionalist unidimensional classes and multidimensional classes, indicating how the unidimensional classes led to more social comparisons and promoted in students the development of an understanding of their abilities based on comparisons with their peers in a system with narrow parameters, under direct control of teachers. Klingner, Vaughn, Schumm, Cohen, and Forgan (1998) pointed out that general educators need to adapt their classroom practices in order to become responsible for the special education students in their classes. Whinnery, King, Evans, and Gable (1995) supported this proposition and affirmed the need for modifications and accommodations for students with disabilities in order to promote their successful inclusion in general education classes.

**Teachers' attitudes.** For some students with disabilities, the consequences of a teacher's negative attitude can be dire. For Farrah, a young woman with a disability, a teacher's negative demeanor and harsh words caused Farrah to neglect her work and lose any impetus to attend school at all. She recounted the following story:

I remember one horrible incident vividly. I came to class this particular day, and my homework was not finished. I explained to her that it was because there were too many problems and I did not quite understand how to do it. All of a sudden, her face got very red, and she screamed at me, "I know you did not belong here. People like you cannot do this type of work!" I was absolutely mortified....When I came home from school that day, I was devastated, and for a while stopped doing any of my homework. I stopped wanting to go to school at all. (Hernton, 2006, pp.60-61)

Her story is not an isolated incident. Unfortunately, conversations with students in special education are rife with retelling of pain and humiliation. It is important that we face the prospect that teachers can—deliberately or inadvertently—inflict emotional injuries on students with disabilities who are vulnerable to the stigma of labels and discriminatory treatment (Farrell et al., 1995; Fitch, 2003; Jones, 2005; Kortering & Braziel, 1999a; Medina & Luna, 2004; Reid & Button, 1995; and Woolfson, Harker, Lowe, Shields, & Mackintosh, 2007).

Farrell et al. (1998) reported that the students they interviewed described classes as interesting, not on the basis of content, but on the nonjudgmental attitude of the teachers. Students consistently mentioned wanting teachers who would support them and help them, and sometimes just notice them. Medina and Luna (2004) cited students who wanted teachers to respect them, to be by their side when they needed help, to talk to them and encourage them, and simply to care about them and listen to them. Angela, a 14 year old expressed her feelings of ostracism, "[The teachers] don't even care about me. I looked sad today and nobody even noticed. [The teachers] don't want me in their classroom" (p. 14). Her sentiments underscore the need for teachers to be aware of how their behavior can have effects that they do not observe. Angela wasn't actively mistreated by her teachers, but she was ignored at a time when she needed assistance, but was prevented—either by cultural or gender-associated barriers—from asking for help. Koertering and Braziel (1999a, 1999b) interviewed former students who had dropped out of school, and ninth graders who were just beginning their high school education, from the perspectives of looking back and looking forward, both groups of participants expressed that caring and supportive teachers, or the lack thereof, were crucial to their remaining in school or dropping out. Teachers need to understand students' perceptions of school; their responsibilities go beyond delivering information and assigning grades. Woolfson et al. (2007)

suggested that teachers may need training and school policies may need to be revised to ensure success for all students, especially students with disabilities.

Self-image of students with disabilities. The social aspects of schooling, from students' perspective, are as important as (if not more important than) academics (Broer et al., 2005; Farrell et al., 1988; Jones, Thorn, Chow, Thompson, & Wilde, 2002; Jones, 2005; Klingner et al., 1998; and Kortering & Braziel, 1999b). When students with disabilities are in segregated classes they become isolated from their peers and the school community. The segregation heightens their sense of being different from their nondisabled school mates as does the constant presence of an educational assistant (Broer et al., 2005). Students who remained in segregated settings developed impressions of themselves as being of lower intelligence than their peers (Whinnery et al., 2007). Fitch (2003) reported that

The longer [the students] remained within the special education classroom, the more they took on a kind of deviant subcultural identity as outsiders. Even as they professed a preference for the perceived safety and anonymity of the special education class, they admitted a secret sense of shame, embarrassment, and desire to eventually escape its confines (pp. 238-239).

Students who are kept away from the school community do not have an opportunity to share in the social and cultural life of the school. Many high school students with visible disabilities can be observed having lunch with each other and with educational assistants instead of with their nondisabled peers. The isolation of the classroom is carried into isolation in all school surroundings and lack of participation in school activities. Broer et al. (2005) found that paraprofessionals, while offering necessary support and assistance also presented barriers to students' ability to interact with their nondisabled peers, even in inclusive classes. Their presence

had a negative effect on how the students with disabilities were perceived by their classmates. By offering individual assistance during lessons and class activities, the paraprofessional also prevented the student from having frequent interactions with the regular classroom teacher. The study also indicated that paraprofessionals are frequently viewed in the roles of mother and friend, both of which are problematic for students in high school. Having a mother figure around constantly does not readily lead to interactions among students.

Angela, a high school senior expressed her frustration with having an educational assistant in attendance all the time.

Once again I was assigned a full-time aide. It was hard enough going to a new school, but try and make friends with an aide following you around from class to class and sitting next to you every day. I couldn't stand it. I would try to have private conversations with my friends, and the aide would always listen in. I'm too old for a babysitter. I needed some privacy at school (Gabel, 2006).

Broer et al. also pointed out that if students with disabilities considered paraprofessionals as their friends, it implied that they had not had enough opportunity to develop friendships with their schoolmates. Students who have not had the opportunity to add their voice to decisions of placement of assignment of educational assistants have been separated from their peers by brick and mortar walls of segregated classrooms or the symbolic walls of a paraprofessionals' presence. Daley and Wesiner (2003) stated that students with disabilities are concerned with the everyday things that concern their nondisabled peers. Many students with disabilities are able to explain their disabilities, when asked to do so, as only one aspect of who they are. Their disabilities do not render them different and teachers should not make the assumption that feelings of dejection are merely a function of their disabilities. Teens with disabilities need the

same compassion and empathy—not pity—that all teens need. A label identifies a particular disability not the person. Teens' message is similar to that of parents: Listen!

In Chapter 2 I reviewed literature related to the subject of this study. I reviewed IDEA and case law related to the rights of parents' and students to a free appropriate public education. I also examined United Nations documents in order to present a world view of the rights of individuals with disabilities including children. I reviewed literature related to teachers and teacher preparation to examine their roles in developing individualized educational programs and including parents and students in the planning process. Finally, I reviewed literature directly related to the voices of parents and students with disabilities in the education process.

# Chapter 3

### Method

Portraiture is the defining method of this study. I wanted to capture the voices and experiences in mini-portraits of the participants. In this chapter I will describe the basic principles of portraiture and its relationship to interpretative phenomenological analysis (IPA). Next I discuss the specific procedures for data collection, including the methods I used to select and contact the participants for inclusion in this study and the circumstances surrounding the individual interviews. I identify the steps I took to ensure rigor in the research process as summarized in Table 1.

#### Portraiture and IPA

In planning and studying research methods, I concluded that Sarah Lawrence-Lightfoot and Jessica Hoffman Davis are the preeminent authorities on portraiture. It was rare to find a journal article dealing with portraiture that did not reference their work. Lawrence-Lightfoot and Davis (1997) described portraiture as

a method of qualitative research that blurs the boundaries of aesthetics and empiricism in an effort to capture the complexity, dynamics, and subtlety of human experience and organizational life. Portraitists seek to record and interpret the perspectives and experience of the people they are studying, documenting their voices and their visions—their authority, knowledge, and wisdom (p. xv).

Lawrence-Lightfoot and Davis (2007) enumerated five essential features of portraiture: Context, which incorporates the setting and all the ramifications of that term; voice, which identifies the voice of the researcher as witness and interpreter of the data and captures the voices of the participants; relationship building, which pursues the complexities of the life experiences of the participants; *emergent themes*, which look for "repetitive refrains" (p.193), symbols and metaphors and ceremonies that "punctuate the lives of a community or institution" (p.201); and the *aesthetic whole*, in which

The portraitist hopes to develop a rich portrayal that will have resonance (in different ways, from different perspectives) with three audiences: with the actors who will see themselves reflected in the story, with the readers who will see no reason to disbelieve it, and with the portraitist herself, whose deep knowledge of the setting and self-critical stance allow her to see the "truth value" in her work (p. 247).

Rhodes (2012) expressed the need to use more than one approach in conducting research. Rhodes stated that "there is a host of more sophisticated methods that allow for a richer description of lived experience" (p. 179). Hendry (2010) supported this position and asserted that there are "multiple ways of coming to know, consequently no one method is sufficient" (p. 76).

Portraiture's methodology combines empiricism with aesthetics and takes a step beyond the traditional methods of educational research. According to Davis (2003) portraiture relies on a "humanistic determination to speak through relevant voices rather than academic codes" (p. 200). Chapman (2005) presented portraiture as an appropriate research method in revealing voices of marginalized groups. Chapman discussed the relationship between portraiture and critical race theory. I substitute critical disability theory and apply Chapman's principles of "emancipatory research [that] is an amalgamation of the researcher's multiple epistemologies, some of which are embraced in current academia and others that struggle to claim a space in the narrow definitions of rigorous research" (p. 37). Thomas and Magilvy (2011) claimed that "the

term qualitative rigor itself is an oxymoron" and that qualitative research is a "journey of explanation and discovery that does not lend to stiff boundaries" (p. 151).

I incorporated concepts and procedures from interpretative phenomenological analysis (IPA), which like portraiture "focuses on personal experiences and meanings" (Todorova, 2011, p. 37), to identify and interpret the lived experiences of the participants.

Smith (2010) listed the skills needed to conduct good IPA as "interviewing, analysis, interpretation, writing" (p.188). Smith (2004) encapsulated the process of IPA: "The participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (p. 40). IPA, like portraiture, seeks to present "interpretive description" (Davis, 2003, p. 201).

# **Participants**

Three former high school students, all male, with intellectual disability consented to participate in this study: David, age 23, Nick, age 25, and Thomas, age 23. They were each identified by their mothers as having an intellectual disability. The other adults who participated were David's mother, Kate and David's adult sister, Meghan; Nick's mother, Carol; and Thomas's mother, Theresa. All of the parents had been natural guardians of the boys while they were in high school, and continued their guardianship throughout the course of this study. The mothers did not state how guardianship was obtained after the young men reached the age of 18. All the participants were white. Parents owned their homes and were employed during the duration of the study. Parents and David's sister all had at least college educations.

The participants in this study represent a purposeful as well as a convenience sample. It is purposeful in that it is "fairly homogenous and share[s] critical similarities related to the research question...and seeks to maximize the depth and richness of the data to address the

research question" (DiCicco-Bloom & Crabtree, 2006, p. 40). It became, of necessity, a convenience sample because recruiting participants was more problematic than I had anticipated. Working in special education as a teacher in the district, teaching courses to teacher candidates at the university, sponsoring a local chapter of a national organization for individuals with intellectual disability, and conducting workshops and presentations in the area, made it difficult to locate individuals with whom I did not have a prior relationship. I had originally planned to interview students within four years of their graduation from high school. I had to abandon that requirement because of my relationships with so many professionals and other individuals within the district. Eventually through personal contacts, I was able to locate former students, with whom I had no direct relationship, and their parents who were willing to take part in my study. They all signed consent forms approved along with the study by the University of New Mexico Institutional Review Board.

Parents and former students were contacted and appointments set up at their convenience. In each case the participating parent was the mother. The location of each interview was determined by their preference as well. I had a private office that was physically amenable to interviews. Additionally, there was a comfortable waiting area to accommodate individuals during interviews. David and his mother and sister, and Nick and his mother decided to meet me there. Thomas and his mother chose to conduct the interview at Thomas's current group home. In my phone conversations with all of the participants, they expressed a preference for reading and evaluating the consent letter at the time of the first interview. Parents and students read and signed the consent forms prior to each interview. In each case I discussed the contents of the consent, clarified language and assertions, and answered any questions that arose. I left the room so that parents and former students were given as much time as they needed in

private to discuss the contents of the consent and to decide whether or not to participate in the study.

### **Interview Process**

I conducted semi-structured interviews, beginning each with an open-ended question similar to "Please tell me what you remember about high school?" The rest of the interview was "organized around a set of predetermined open-ended questions with other questions emerging from the dialogue" (DiCicco-Bloom & Crabtreee, 2006, p. 315). The planned questions dealt with issues around teachers, friends, activities, IEPs, and transition. A list of typical questions is included in the Appendix. Recognizing however that "interviews often do not proceed as planned" (Roulston, 2011, p. 349) each interview followed the digressions and comments of the participant in order to reflect that person's interests and voice and, according to Smith (1996), to "explore the participant's view of the world" (p. 264). Smith (2004) saw the advantage of the semi-structured interview in that "the researcher is, in real-time, in a position to follow up interesting and important issues that come up during the interview" (p. 50).

After the procedures surrounding the consent forms were completed, I began each interview with a grand tour question. With little variation in wording the initial question was: "Tell me about your experiences in high school." I followed up with further questions to elicit information about the high school environment. Typical questions that I used in the interviews are included in the Appendix. DiCicco-Bloom and Crabtree (2006) stated that the interview "is based on the meanings that life experiences hold for the interviewees" (p. 314). I asked many unplanned questions based on the interviewees' responses in order to add detail and depth to my understanding of their experiences. I provided a list of questions to Thomas prior to the

interview because his mother told me that he would be more comfortable if he felt prepared. For all other participants, the first time they heard the questions was at the actual interview.

#### **Interview contexts**

David, Kate, and Meghan. David and his mother arrived together; David chose to be interviewed first. Due to technical problems, I was not able to audio-record his first interview. David graciously agreed to return at a future date and allow me to record a second interview. I did conduct an interview with David's mother at that time. Her interview lasted approximately 35 minutes. David returned two weeks later with his adult sister. I interviewed David again; this interview lasted about 40 minutes. Although I had not included family members other than parents in my original proposal I filed an addendum to interview his sister because of the close relationship that David revealed they shared. Her interview lasted about 20 minutes. David was not in the room during either his mother's or his sister's interview. There were no interruptions or untoward events during any of these interviews.

**Nick and Carol.** I interviewed Nick and his mother in a private office as well. Nick chose to wait until I had completed the interview with his mother. Her interview lasted approximately 45 minutes. I interviewed Nick immediately after this; his interview lasted 25 minutes. There were no interruptions during these interviews.

Thomas and Theresa. Theresa, Thomas's mother had advised me that Thomas had difficulty answering open ended questions. I provided a written list of seven questions via e-mail prior to the interview so that Thomas would feel prepared. These questions are the same or similar to questions I asked of each former student participant.

I interviewed Thomas and his mother at Thomas's group home. Theresa arrived before

Thomas and we conducted the interview in a small office in the front of the house. Theresa's

interview lasted a little over an hour. At that time, we heard Thomas arrive home. She called him into the room and introduced me and encouraged him to take part in the interview. As mentioned earlier, we discussed the consent form thoroughly before he agreed to participate. The interview with Thomas was interrupted more than once by activities in the house. I believe under the guise of household chores, many of the residents were curious about what was going on in their home.

### **Ensuring Rigor**

I maintained a detailed audit trail of the interview process, the dates, times, locations, and durations of the interviews and the circumstances under which each interview occurred. I transcribed each recorded interview myself, reviewing each section repeatedly as I proceeded. I redacted each transcript and replaced the names of the participants with pseudonyms. I changed the names of any locations, schools, and any other organizations that might disclose the identity of the participants. As recommended by DiCicco-Bloom and Crabtree (2006) I listened to each recording again while reading the transcripts to check that I had been as accurate as possible in my transcription. I transferred the digital recordings to my computer so that I could password protect them and erased the original digital recordings. My data is backed up by Carbonite, a commercial, cloud-based storage system, where it is also protected by password.

Each transcript was reviewed and examined numerous times in order to produce a coherent story that presented the participants as authentically as possible. In order to simplify references within the text of my report, I combined the individual transcripts into one consolidated transcript and paginated the final compilation. The stories contain thick description of the participants, their conversations, and the circumstances surrounding the interview sessions. The data are presented in the portraits. As a way to incorporate member checking, I

sent the individual portraits to the participants via e-mail in order for them to verify the accuracy of my portrayal of them. Based on their responses I made minor adjustments without changing the integrity of the original portraits.

A fellow doctoral candidate examined the redacted data and the portraits, confirmed my findings and helped me to identify other concepts embedded in the data. I did not calculate a formal inter-rater reliability because of the interpretative nature of the study. Yardley (2000) supported this position: "Although it is feasible to train two people to code a text the same way, this does not exclude the element of subjectivity in the interpretation of the data – it simply becomes and interpretation agreed by two people" (p. 218). I maintained constant contact with the members of my dissertation committee and relied on their expertise to ensure that I portrayed the participants fairly and presented their stories accurately.

My adviser noted those instances when I might have allowed my viewpoint to unfairly color the responses of the participants and I edited those sections to present their conversations with more objectivity. I realize that "pure" objectivity is not possible and revealed the personal biases that may have influenced this study. I recognized that my interpretation of the respondents' conversations was influenced by my current position as a high school teacher in both general and special education and my role as an instructor of teacher candidates at the university, and disclosed the critical theory lens through which I view the current system of education.

Brantlinger et al. (2005) posited a number of credibility measures – audit trail, thick description, member checking, peer debriefing and investigator triangulation, and researcher reflexivity – that have been addressed above. A summary of the credibility measures and their relationship to this study can be found in Table 1.

Table 1. Summary of credibility measures and compliance methods to insure rigor

Credibility measure	Compliance in my study
,	1 7 7
Investigator triangulation	Fellow doctoral student as consultant
Methodological triangulation	Combination of Portraiture and Interpretative Phenomenological Analysis
Disconfirming evidence	Recognition of contradictions in interviews
Researcher reflexivity	Disclosure of critical theory stance as well as position as teacher of high school students with disabilities.
Member check	Drafts of portraits were sent to participants
External auditors	Consultation with peer and dissertation committee members
Peer debriefing	Consultation with colleague/doctoral candidate
Audit trail	Interview processes, dates, times, locations, duration, as well as circumstances surrounding all interviews
Thick description	Detailed descriptions of participants and interviews included
Particularization	Documented through description and identification of role of each participant

Note: Credibility measures from Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005).

In this chapter I presented the properties of portraiture and interpretative phenomenological analysis as the research methods I chose to use in my study. I included information about procedures including choice of sample, interview procedures and contexts and my efforts to ensure credibility.

# Chapter 4

### Results

This chapter contains the findings of my study framed in individual portraits of the participants. The seven portraits stand on their own as a way to allow each participant's voice to be heard.

### The Portraits

David. The first time I met David I was taken by the strength in his voice and the confidence he exuded. He entered the room and shook my hand firmly and greeted me politely. After disposing of the necessary business of consent forms, I began our interview. He was forthcoming and articulate in his descriptions of his high school experiences. At the end of the interview process, my own technological inadequacies came to the fore when we discovered that I had not recorded one word of our conversation. Embarrassed and apologetic, I asked David if he would be willing to come back on another day and redo what we had just done. He was cheerful and understanding and we made arrangements for him to return the following week with his sister.

The second time I met David, he said it was "OK if you don't know how to work [the recorder]." After politely but firmly rejecting the clip art pictures I thought might be helpful in telling his story, David responded to my request to make up a story about a boy in high school. He spoke energetically about a boy named Roger who had come to Desert City from another state and had a good time in high school. Roger went to the main office every day and talked to the persons there, ate lunch, and played with his cell phone. But then, he had his phone taken away.

He was being obsessed with his phone and so...he just...he was just having a good time in high school and then one time he...uh...I don't know if he got expelled in high school or if he...or if he...or if he didn't get expelled because he was always on time in high school, never late to class. He didn't give the teachers any problems. He was a good student in high school. But if he was a good student in high school, I don't know why his...his phone would be taken away in high school (Transcript, p. 1).

He revealed shortly thereafter that the story was really about him. It was an amalgam of two incidents which he conflated. One was a story about himself; the other was told to him by his brother-in-law.

David recalled another incident when he was caught ditching and the consequences that ensued. He said, "One day...one day I...one day I would ditch school and I would ditch a lot at Hilltop and....But I'd have nowhere else to go when I would go off campus, but I mean...I mean I couldn't drive anyway but..." (Transcript, p. 7).

#### He said he ditched

Because I felt the classes were too long and so I wanted to get out and go do my own thing even though I couldn't do my own thing 'cause I don't have a car. I can't see real good. I don't even know how to...how to manage money. Like...like I don't know how to count change. Like if I were to go buy something, they would say give me the correct change and I wouldn't...wouldn't know how to do it (Transcript, p. 7).

David, like his avatar, Roger, would go to the front office and hang out until his teacher discovered him there. At that time he would try to hide in the rest room, and when he got caught "They would tell Meghan [his sister]. They would tell my parents. They would tell whoever. They would write this big old note..." (Transcript, p. 7).

David, as do some special education students, stayed in high school until he turned 22. In the course of this time, he attended three different high schools. Occasionally he became confused about where different incidents had occurred. Regardless of what had happened at each school, David reported that he was happy with his school experiences. He spoke of one of the schools where it was "AOK. It was fine. It was fine. I liked the food there and I liked everybody at Hilltop. It was a...it was the best thing" (Transcript, p. 2).

David spoke enthusiastically about his high school experiences. He cited some of the good parts of high school were field trips. He recalled them as

fun and educational. . . They weren't like boring field trips like...um...like I need you to write down this thing on a piece of paper. Write down how many animals there are.

Write down how many zebras and everything else and monkeys (Transcript, p. 6).

I asked David to tell me about the teachers he had in high school. He told me he liked his teachers.

My teachers they were always there for me. Like...like if I needed stuff done like...like they were never mean to me. But if like they wanted me to do paperwork, I would just get on and do paperwork. I wasn't...I wasn't pushing or mad or stressed out or anything. They...they were always wanting me to do paperwork and so and...and I was OK with that. I went with the flow. I mean I knew what school was and I took it seriously. I didn't take it as a game or where I just...where I just went to recess every day...but high school's high school. You don't get to go to recess every day in high school. You sit in the class and learn (Transcript, p. 7).

I commented to David that he said his teachers "were never mean" and I asked what good teachers should be like. He stated that teachers should treat their students

with respect, goodness and ...and not mean. But I know it's kind of by the book in some other schools where they kind of treat their students differently. But...but if I was a teacher I would just treat them like...like how they wanted to be treated. Like I wouldn't be like a mean teacher. I'd be like...I'd be like not mean to a student. No, I wouldn't be mean to a student at all (Transcript, p. 10).

When I asked about his favorite teacher he said it was his sister who was his teacher during his final year of high school at Riverview. David said that she was his favorite teacher because "she was very like by the book. She always told me to do my work and I did it. I completed high school." He added that his sister helped him to become manager of the Riverview cheerleading squad.

I was the manager. But I...I didn't get thrown up in the air or anything. But I wish I would have been thrown up in the air....I just...um...talked to the cheerleaders. Um...they showed me one cheer like this one like [Clap, clap clap] Go big red. You know. That's what they did. I only...I only knew one cheer. It's sad. I wish I knew a lot of them (Transcript, p. 4).

I asked David what he remembered about his IEP meetings. He said the "meetings were always good." He recalled a specific meeting where

They just wrote down a bunch of stuff in my IEP meeting about me like...like a lot of nice stuff, but some stuff what [sii] I would have a lot of anxiety and stuff and wouldn't come to school for two days and I would be kind of depressing....They didn't ask me, but it just said in the IEP...it just said David will have like a nervous breakdown where he doesn't come to school for a few days and...(Transcript, p. 4).

I inferred from his description that the choice to stay home was David's. As he continued, however, he revealed that the school did not want him to attend at certain times. Unlike the bulk of David's reminiscences, this story was heavy with hesitation and uncertainty.

...because of my anxiety they didn't want me at school a lot 'cause of...'cause of...because I would just...I would be a com...completely different person when I had that. But I don't have that anymore. Oh I still do but I do get anxious but not very much.....Yes and it was true. It wasn't a lie. 'Cause...'cause even...even a while back, back in December when I had the psychosis it was terrible and I thought about Hilltop back then and now I know it's past and I've got to leave it alone (Transcript, p. 6).

When I asked David what else he did at school his response indicated that spent a lot of time with adults in school. He spoke more than once about spending time in the school office. "I...I would...I would just go up to the office and talk to all the representatives, which in a nice way, but that would be bugging them. I would bug them..." (Transcript, p. 2) When he ditched classes he "would just go to the front office and just hang out there" (Transcript, p. 7) Even when he spoke of one of his friends, he recounted a time when they were "having a good old time with the teacher" (Transcript, p.3). He spoke about times when all of his classes were "like finished," and he would go to see the counselor and "go sit with her....But now the thing is I still volunteer with her every single time I go there to volunteer...She's a nice counselor at Riverview. And I don't ...I don't ...I don't ever want to stop volunteering" (Transcript, p. 10).

I asked him if he still liked to volunteer. David said he continued to volunteer after he graduated from high school. "Like today I went out with our church. We go out in the field ministry. We...uh...preach the good news and...and that's what we do" (Transcript, p. 11). Aside from volunteering for his church and spending time with his family, David planned to work with

a job developer to find a job. When he discussed his plans he revealed his sister Meghan's influence both in choosing a potential position and in encouraging David to recognize his strengths.

Well, Meghan was thinking Salon Therapy which would be perfect for me.... I think Salon Therapy would be good for me because it's very calm and very relaxing in there. And I think it would be fine for me because...because...I kind of told Meghan I did not want to work at Salon Therapy. But then she was like, David, no don't say that. And so...and so...but then I just...I just said to myself...I just said to myself I guess I'll just try it and see how it...how it goes. Because I'm good at answering phones. I'm very professional on the phone. When I...when I answer it I'm like "Hello" and stuff and I'm like...I'm...I leave very professional messages and stuff (Transcript, p. 12).

I asked David if his sister helped him in other ways. David explained that he spent part of each week living with his sister and his brother-in-law.

I stay with my sister during the week...um...sometimes during the week. But when school starts they'll be back to...on Tuesdays I'll be staying with them during the week but...um...and so....But I like staying at their house. They're...I mean Jacob's...Jacob's such a good brother-in-law...and I give him credit for...for him being so good to me (Transcript, p. 12).

*Kate, David's mother.* My meeting with Kate, David's mother, began at her car window. The maze of parking lot entrances and exits sent her to the wrong location. In a caravan of two, we arrived at the office where we would conduct our interview. Kate was cheerful and good spirited about the difficulty in locating the office.

There was a touch of deference in Kate' reaction to me. I believe that because she was a new special education teacher, it is possible that she may have been reluctant to say something that might not be acceptable to a veteran teacher. I reassured her that it was *her* story I wanted to hear and did not care how our opinions synced or diverged.

When I asked Kate about David's high school experiences, she began by telling me about David's experiences in pre-school and talked about the decline in services over time. She prefaced her comments with a remark that

This was before I was a teacher...Every time he got older and in a different grade, things weren't as good. That's what I always felt. Services weren't as good; teachers weren't as good. When high school came, it was kind of an awakening. Things didn't revolve around him....High school was just different...different than when he was little (Transcript, p. 13).

Kate mentioned again later that "you get a lot more during...from first grade through middle school...High school it was harder for me to call the shots" (Transcript, p. 15).

I asked Kate if her son had been in general education. Kate described the difficulty she encountered in finding the right placement for David.

They wanted to place him right away in ISP [Intensive Support Program], in high school and I said no. So I...so CRL [Community Referenced Learning] seemed better and that was OK, but I also wanted him to be in general ed classes with typical kids....They wouldn't put him in...um...in regular general ed classes....I wanted him to be able to read with them and...and just be with typical kids. Well, they didn't want to do that (Transcript, p. 14).

Other than in electives, David never was placed in general education classes in any of the high schools he attended. Kate said that he enjoyed those elective classes because he's "more of a social guy" (Transcript, p. 15).

I asked what she thought the schools should have done differently. Kate recommended that general education class sizes should be smaller, and despite the displeasure with general education teachers that she expressed later, she made allowances for their resistance to inclusion. "General ed teachers, they have, you know, there's a lot on their plate. I know that. I mean they've got a lot of students with a lot of grading and things like that" (Transcript, p.18).

David was placed in what were called D-level classes where there were many behavior issues with the other students. "So he didn't fit in there either....It was always behavior with the other kids and he'd come home and say, "They were mean to me and they said the F word" (Transcript, p. 14). Without being specific but sounding definite about her opinion, she later described his special education classes as a "disaster" (Transcript, p. 15).

Kate expressed that CRL classes were a better fit, but hesitated before she said they were "OK." She recalled David's experience in a CRL class.

I think about how instead of them teaching him things that I thought he should learn, they just did things like cooking, like getting a big recipe and cooking up this big recipe and I never could figure out why they would go out and cook a big old recipe. Why aren't they teaching him to make a sandwich or to microwave a thing? So I never was really thrilled with any of his classes and that's probably why I decided to go to school (Transcript, p. 14).

Kate had just recently finished a teacher education program and was in her first years of teaching special education. This may have influenced her portrayal of one of her son's teachers. Kate spoke at length about one of David's support teachers at Hilltop High School.

I didn't feel like she was a good teacher and I felt like she had issues of her own and it spilled over onto the classroom....Academically I think she was spread a little thin....I think, if I remember correctly, when he was in her classroom there were maybe ten kids and all on different levels and I think it was hard for her to try to teach math and reading to him on his level....I don't think she had any consistence to teaching him....She was young and I don't think she was seasoned...and I don't think she really had it together....I'm not putting her down for that, but I think she was a little bit...just new and green (Transcript, p. 17).

On the positive side, however, Kate remarked that this teacher tried to "get the kids out into the community" (Transcript, p. 19) and found David "like a little job like folding towels at the 99 Cent Store...um...folding towels at the Bargain Six Motel, things like that" (Transcript, p. 16). I asked if this teacher recognized the sociability she had mentioned earlier and if she helped him with his social interactions. Kate responded, "No, I don't think so. I don't think she did anything out of the ordinary to make...um...she didn't do anything like you know [She glanced at and pointed to a Best Buddies sign in the room.] make a peer buddy classroom or things like that or Special Olympics or anything like that" (Transcript, p. 16).

David did have a high school teacher who Kate thought was good. "Mr. Langston was good....He was more of a seasoned teacher and talked a lot about...mm...hygiene and real things that I thought...and I thought he was good for doing things like that" (Transcript, p. 17).

My meeting with David convinced me that he was articulate and poised. I asked Kate how she thought he had become self-confident. Kate attributed David's current success and his reading ability to David's older sister, Meghan and herself.

When I asked about David's IEP meetings Kate said that she was treated well by the staff, but expressed dismay about the IEPs themselves. "They always sound better than what the reality is when you finally get out.... Like everybody's around him and they're all brainstorming and figuring out what to do and then he gets back and you know...the reality is never as good as the fantasy" (Transcript, p. 14).

I asked if David had taken part in extracurricular activities. Kate indicated that he was not involved in any school activities until his last year at Riverview when he worked with the cheerleaders. "He...um...they allowed him to be the manager of the team. He would go after school and watch them practice and things like that" (Transcript, p. 17).

Kate was critical of high school programs: "High schools have a lot to work on with kids with intellectual disabilities" (Transcript, p. 18). Kate had a lot to say about the attitudes that surround inclusion of kids with intellectual disabilities in the general education setting.

I think that general ed teachers should have welcomed him in their classes just like any other student. And I don't think even now that we have to go to these general ed teachers and say, "Can my student come in your class?" I don't think we should have to ask a general ed teacher if students can go into their classroom when it could just be a right like any other student and that was...and that happened with David (Transcript, p. 18).

Kate expressed that "the inclusion that we all talk about and we all want I don't see it as...I guess if it was a perfect world it would be a perfect thing, but it's not" (Transcript, p. 18).

All in all, according to Kate, David's high school experiences were good for him, "He left happy....He'd love to go back" (Transcript, p. 19). Kate expressed doubt about her decision to keep David in high school until age 22 because it became "too comfortable" (Transcript, p. 19) for him and made it hard to leave.

It was a hard transition for him not to go back to high school....So I think I might have done that different and I might tell parents that you might want to think about that if they get really, you know...you just get so used to something and then you're in a safe little environment and everybody likes you and you know you're there six and half hours a day and all of a sudden – "See ya" (Transcript, p. 19).

I followed up on her mention of transition and asked her about her family's experience with district programs. Kate expressed that the school system did not provide adequate transition services. She said that perhaps she might "have done a little bit more research" (Transcript, p. 19). However she thought the school district "dropped the ball" (Transcript, p. 19). Desert City District Postsecondary Training Program (PTP) placed him in a job but He didn't get much support....they expected him to just be able to do it. And he had a hard time doing it, and instead of supporting him a little bit more they just like—"Oh well, this isn't going to work out. Let's think of something else." I didn't see a lot of PTP coming in there and helping to provide this [support] with David (Transcript, p. 19).

Kate transferred David to Riverview for his final school year where he was in a class taught by his sister who helped him while he was there. Kate demonstrated her reluctance to confront school personnel.

I kind of let Meghan do it because it was kind of hard. I always felt like I was too much the mother and too much the teacher, and I just you know...you get confused. I wanted so much but you don't want people to get mad. So I let Meghan do it (Transcript. p. 20).

Throughout the interview, Kate demonstrated a conciliatory attitude. That made her final statements surprising until I considered that she was now in the position of being a teacher with some influence in school policy instead of a parent with little power to effect change. Kate's final words were advice to parents whose children were entering high school. "Go with your gut and then fight for what you want. And take it to the top. That's what I tell all of my parents" (Transcript, p. 20).

Meghan, David's sister. I did not anticipate interviewing Megan because I had worked with her during her student teaching. However, she had driven David to his second interview and I knew from talking with him and his mother, that she played a pivotal role in David's life. She is a young teacher in her mid twenties and works at Riverview High School where she has been responsible for a number of changes in their special education program. She initiated a peer buddy program, became program director for Special Olympics, and worked with general education teachers to include students with disabilities in their classes. She is an ardent and outspoken advocate for inclusive education. Her ebullient demeanor made it easy to see how she was able to wield such influence at Riverview despite her young age.

Meghan listed the three different high schools that David attended: Hilltop, where David attended for five years; Midlands, where he stayed for a year; and then Riverview for his final year. Meghan described his experiences at each school

Each school was different. Hilltop was very segregated...except for that my mom was able to fight for him to be in some classes, but I think then they would say "OK, we'll

put him in an inclusion class" and they ended up putting him in like a cross-cat [cross categorical] special ed class....It just never really worked. Like they just couldn't get it....The reading classes and the language arts where we really wanted him, he never got into.

Midlands was even more segregated than Hilltop. They had an art class for elective, but only kids with disabilities were in it. They wouldn't let [David] go to lunch. He had to eat with the group. Then we figured how to get him into Riverview. He did other things. He wasn't as segregated (Transcript. pp. 21-22).

Meghan talked about David's mental illness, a major cause for his move from school to school. He developed a psychosis and became obsessed with one of the Hilltop teachers so they "had to get him away from Hilltop" (Transcript, p. 22). Meghan expressed dismay at the segregation in Midlands, "But at that point that really wasn't what mattered. It was just getting him somewhere safe and having him in Desert City where if he started to have a lot of anxiety we could be there" (Transcript. p 22).

David was still recovering when he transferred to Riverview where the ongoing titration of his medications caused him to be extremely tired so that he spent a great deal of time asleep on the couch in Meghan's classroom. "But when he wasn't on the couch, he went to cheerleading class" (Transcript, p. 22).

I asked Meghan what he would do now that he was out of high school. She said that she and her family were helping him on their own, "filling out applications and stuff...um...we want to get him a little job and trying to get him more independent" (Transcript, p. 24). Meghan stated that the family was assisting David because she thought that the job developers he was

working with "don't seem as motivated as they should be" (Transcript, p. 24). Her further comments indicated that he was able to do many things by himself.

He rides Mesa Transport by himself—everywhere. So he kind of has his own transportation and he calls it up. And he does it all by himself. He books his trips. We're just trying to get him more independent. I think eventually we really hope to have like a house with a house in the backyard and let him have his own little kind of apartment place and a little job and stuff like that (Transcript, p. 24).

In looking back at David's education, Meghan offered some suggestions about what she would have changed. "He should have been in a general ed English class. Like, hands down I think his writing and his reading would be even higher than it is already is with that....He has a really hard time with math....He needed more math" (Transcript, p. 24).

According to Meghan, David had a lot of friends, "more general ed than special ed friends for sure" (Transcript, p. 24). But then she added wistfully,

Sometimes I wish he could've had a friend with a disability, 'cause I think he might have connected with a...on some other level and he never did. And maybe they could have developed a closer friendship than the friendships that he developed. But he never...he doesn't want to hang out with kids with disabilities. He just didn't (Transcript, p. 24).

Nick. When I met Nick and Carol in the parking lot, Nick became involved in our conversation about the new construction that he noticed. He was articulate and animated. He greeted me formally with a firm handshake, and held the door open for his mother and me. His graciousness continued as he offered to let his mother go first with her interview while he waited. Throughout the interview, Nick's eyes flashed and he spoke with authority and enthusiasm. As the interviewer I believed it was my responsibility to put Nick at ease. However

his natural friendliness and charm reversed our roles and he made me feel comfortable, even as I fumbled with the recorder. I enjoyed our conversation.

When I asked Nick to tell me a story about a boy in high school, he responded with "a real story" of being bullied.

Some kids were making fun of me and they were taking my lunch money and these...these football players...um...saw what happened and came running – all 20 guys came running in, came running and stopping....They went...tackled these two kids and pushed them into a locker and bent them...bent a locker....Now I had the whole school...um...as my backup (Transcript, p. 25).

He later told me that he stands up for his friends, "They knew when they messed with my friends, they would have to deal with me" (Transcript, p. 29).

Nick didn't need any prompting to talk about his high school experiences. He said he thinks "high school is awesome" (Transcript, p. 34). When I asked him to tell me about the "worst" part of high school her responded, "Nothing at all" (Transcript p. 29). He related that he participated in many activities in high school. He mentioned a particular highlight. "I was...in 2003, my senior year, I won homecoming king....Yeah, it was so amazing. I got involved with the whole school" (Transcript, p. 26). That involvement included being part of the school's student council.

Wake up every morning by four o'clock in the morning and be in the school before everybody...before everybody else because we planned...we planned all the events and...also...um getting ready for the day. Like for the...for the morning announcements...We....um...we are in this big building by ourselves and unlike senior year the student council...the freshmen, the junior...the junior years and the sophomores

had to give the school...give the seniors a gift, saying goodbye. So, I got a movie called Adam Sandler, Mr. Deeds 'cause I'm the one that loves hugs...giving out the hugs...I...mmm...I just love hugging. It's so much fun (Transcript p. 30).

Nick also took part in student council events with other schools. "We had this retreat with a different school like Bedford Hills. And going on this retreat to somewhere and have lots of fun" (Transcript, p. 29).

Besides student council, Nick was active in Special Olympics and helped to organize a Cortez High School team.

I'm the one that created Special Olympics at Cortez. Cortez never had Special Olympics before. I'm the one that created it by myself and got a coach to coach us....Our first year – Special Olympics – we won...we won our very first gold medal, first ever and brought it back to Cortez and we...I got to announce it at the winter sports assembly. And the whole...at the end when...after we did our team cheer, at the end, the whole student body stood on their feet, clapping for us – a ten minute standing ovation (Transcript, p. 28).

Nick continued his involvement with Special Olympics as a global messenger. "Yeah. I go around the state and I give speeches to parents, like mom and dads, to get their kids in Special Olympics. And...um...tell them about the...the message" (Transcript, p. 33).

I asked Nick about his high school friends. He said he enjoyed being with them. During his senior year, when seniors are allowed to leave campus during lunch, Nick wanted to join them. "Yeah, when I was in school I wanted to go out with my friends. Like I was a senior...senior...I was still in the special ed, my teachers wouldn't let me go" (Transcript, p. 31). The students who did not leave campus ate lunch in the courtyard of the school. "We had to stay in a big group. We can't be hanging out with our friends" (Transcript, p. 31). Nick

remedied that situation by speaking directly to the principal who arranged for Nick to be with his senior classmates for lunch -- off campus. This was important for Nick. He said, "OK, all my friends love me 'cause I'm like part of everybody in the world" (Transcript, p. 32).

Nick spoke about a special friendship with his "best friend," Monica. He met her when he was a sophomore. She helped him get his first job "at a place called Burgers and More. It was pretty awesome" (Transcript, p. 26). Their friendship went deeper than that; she was his friend all through high school.

Yup. And I told her when she got...I told her in high school that I want to be your best man when she got married. And she did. She got married in Cancun, Mexico to a guy named Brad and I got to be the best man and gave the ring. It was an amazing thing (Transcript, p. 26).

I asked Nick to talk about his teachers. Nick expressed that "Being a good teacher is teaching me all those...like math and learning how to read and stuff" (Transcript, p. 32). and that "they'll teach you what you should learn in college" (Transcript, p. 34). Nick thought that his teachers were "OK" and spoke of two who stood out as special to him because "they helped me like we did home ec, like learning to cook and stuff like that" (Transcript, p. 28). I asked if he had ever had an educational assistant. He said that he had a few EAs, "but they...they didn't work out" (Transcript, p. 30). He described an incident with a particular paraprofessional. "One of them...one of the teachers, one of my assistant ones....I was in this class of working with clay, and she just grabbed my hand and made me pinch the clay....That...that did not feel good" (Transcript, p. 30). He did not let that incident go without remedy: "I told the...the teacher...and sent her away and I stayed in the class" (Transcript, p. 31).

At his high school graduation Nick received an award as student of the year.

And I got like outstanding student in special education. All the...all the teachers in the special ed department got together and they voted for the student...for the outstanding student ....And when I got student of the year everybody cheered and my dad spoke, gave a speech and made everybody...and made all the girls cry at that speech (Transcript, p. 32).

After graduation, Nick attended a special program for students with disabilities at South State University in Redlands. "After my graduation I got this paper...got accepted to college right away....It was a fun time. Four years of college" (Transcript, p. 33).

I asked who had helped him apply to South State. He stated that no one at his high school helped him find this placement that he did that on his own. He said that his training at college prepared him to run a restaurant business of his own. "I learned to cook in college. I worked in about 10 restaurants in college....I did restaurant hosting from the front...in the front and greeted my guests at the front door and seating for...at the table" (Transcript, pp. 34-35). With the help of his parents, Nick currently runs a successful restaurant that has become a local attraction in Desert City where hugs are on the menu.

Carol, Nick's mother. I met Carol and Nick in the parking lot. After a brief introduction, Carol's outgoing nature became apparent immediately. She began a conversation about the recent renovations to the building where we were meeting. She seamlessly drew Nick into the conversation. It seemed to me that including Nick was a commonplace interaction between Nick and his mother. I could see Carol's good humor in her warm smile. When I thanked her for her time, she said that she was happy to be part of the study and was eager to answer my questions. Although I knew Carol and Nick had driven across town, Carol said that

she did not consider it an inconvenience at all. She remained upbeat throughout our conversation.

I asked Carol if she would tell me about her experiences with Nick in high school. She stated that Nick's experience at Cortez High School was generally positive. She recognized the importance of Nick's attending his home school "because he went to school with all his brothers and all the kids he grew up with" (Transcript, p. 36). Carol indicated that she was a strong advocate for inclusion; however, when Nick started high school she followed advice from a special education teacher that proved, in this instance, to be beneficial for Nick.

Carol said that Nick had never ridden in the special education buses. "And so in high school I was just going to have him ride to school with his brothers" (Transcript, p. 36). However, Nick's support teacher suggested that he might do better riding with the other students from the small group special education class because the students in her class "become friends and it's an important part of the school day" (Transcript, p. 36). Carol and her husband agreed and

Nick took that concept and ran with it. And he made it part of all Cortez not just his class....I think it was a really, really important foundation that got laid that made all the difference for Nick socially in high school and beyond....That worked for us and for our family (Transcript, p. 36).

I asked her to tell me more about his special education classes. Carol was positive about Nick's time in some small group classes, specifically classes that incorporated community based instruction in 9<sup>th</sup> and 10<sup>th</sup> grade. She stated,

That was very much more important to me in some ways for where I see Nick going than academically...the basic necessities that now will allow Nick to live on his own. I

mean, you can't measure that.... [The teacher] built her kids up at the level they could be built up. She was amazing and she drew in a good group of support people (Transcript, p. 37).

Carol said more about support personnel. She was a "little hesitant to praise some of the support people....Sometimes they [related services personnel] come in and they do too much for the kids" (Transcript, p. 39). However, she had high praise for Nick's speech and language pathologists and called them "phenomenal" (Transcript, p. 39) and said she was grateful for their support of her son. Nick's speech was clear and didn't need remediation, so the speech language specialists worked on communication tailored to Nick's needs. Carol contended that "kids with Down Syndrome tend to be 'I' people" (Transcript, p. 39). Speech language personnel "helped develop a curriculum and a program throughout the years that they worked with him to get him where conversation was more back and forth. And that's really, I mean, key to what he's doing now in his life too" (Transcript, p. 39).

Carol remembered another teacher who adapted curriculum to meet students' needs, Nick's Adaptive PE teacher who came to Cortez High School at the end of Nick's freshman year.

She saw an opportunity because she came to a Special Olympics event that Nick was involved in...and through an evolution, a very quick evolution, she made her adaptive PE class into a Special Olympics team and they competed as Cortez. They competed with Cortez jerseys. She got them attendance at the sports assemblies, introduced in front of the whole school as Cortez athletes and...they earned their athletic letters (Transcript, p. 40).

I asked if she saw this positive pattern of accommodation in other areas of Nick's high school years. Carol was not as enthusiastic about Nick's program in 11<sup>th</sup> and 12<sup>th</sup> grades. She and other concerned parents occasionally observed the class and expressed their displeasure with his teacher. The parents noticed that the students "spent a lot of time just sitting there watching TV" (Transcript, p. 40). Carol commented that the teacher was "just counting the minutes," (Transcript, p. 41). and didn't continue the community based instruction program. "I didn't really see anything super educational. She was supposed to be teaching them how to interview for jobs, how to write a job resume. Never saw the resume. Never heard of them practicing interviewing for jobs" (Transcript, p. 41).

I was appreciative of Carol's insights when I asked about Nick's IEP meetings. Carol spoke at length about Nick's IEPs and said that they are called individualized education plans, but that these plans were "really for the system" (Transcript p. 37) and that they "probably helped the teachers more than it helped us" (Transcript, p. 39). She stated that when the school considered Nick's placement school-based members of the IEP team would say

"OK here comes a young man and he has Down syndrome, so he probably has these attributes," and those probably end up in IEPs. And I think it was really difficult for them to look at who Nick was and what he was capable of....There were a lot of times when I would tell them, "You know, Nick is doing this already," and they just kind of had to see it for themselves (Transcript, pp. 38-39).

She spoke again later about the lack of individualization: "I know it's a state requirement, but I know that you can't...how do you take a person, put these boxes around and say, 'This is the education that they need" (Transcript, p. 43). She stated that more than once she and her

husband would just go along with what was included in the IEP and then work with individual teachers to see that Nick got the help he needed.

I didn't go in and try to make organizational change. Every year I would go in to whatever teacher he was assigned to and go "I believe in inclusion. We don't have it here. I think it's really important. What can we do?" that worked every year with different teachers. And I got tired of it. By the time he got to high school, I didn't fight for that (Transcript, p. 38).

During our conversations, as it was when she first introduced herself, Carol's demeanor was relaxed and friendly, certainly not intimidating. When she spoke about their participation in the IEP meetings, she chuckled.

When the groups first met us, I think they were ready for a fight, which is really interesting because we're not fighters....We said this is what he can do and this is what we would like for him to do, but we didn't feel like we were fighting. But we always felt like it was somehow our job to go in and calm everybody down and say we're not here to fight you. We know there's these laws and these laws and these laws, but here's Nick and here's your school and your program and OK, what can we do? (Transcript, pp. 37-38).

Carol asked that Nick be included in some general education classes and he was allowed to attend. She commented, "I don't recall asking for one that he couldn't go to, but I didn't set my sights very high on that one" (Transcript, p. 38).

When I met Nick earlier, before we settled in for the interviews, I recognized that he was self-assured and outspoken. I asked if Nick had any part in making choices for himself. Carol spoke of Nick advocating for himself. She described one instance when Nick was a senior.

Well, he knew that when you were a senior at Cortez High School you can leave campus and go to lunch, and he was determined that he was going to leave campus and go to lunch, and he worked the system to get permission to go....He did this himself...He got their permission and they made sure he was safe, but he got to go across the street to the burrito place (Transcript, p. 41).

Nick persisted in seeking what he wanted. According to Carol, he said, "OK this is what I want and I'm going to get it" (Transcript, p. 41). She added that this determination is what prompted him to run for homecoming king.

Being elected homecoming king is quite a coup for high school seniors. It requires a high degree of popularity among the entire student body, not just the special education students. I asked Carol about Nick's friends outside of his small group classes. She confirmed that Nick made many friends among the students in the general education population. Carol told of a story of one special friend stood out among the many.

[Monica] was new to Cortez—beautiful....She's just stunningly gorgeous. She met Nick in the courtyard during one of the lunches when he was going around meeting everybody and they became best friends. She loved Nick for who he was.... [Nick and Monica] stayed friends. When she met the man she was going to marry, of course, Nick was part of their lives...and she asked Nick to be in the wedding party...And then it came time for [Brett] to pick who the best man was, and it struck him that Monica had once told him a story that everyone is best friends—you're my new best friend...Bret had to pick somebody to be best man. And he goes, "No, I can't do it. But because of Nick, I'm telling all the guys at my wedding they are all best men" (Transcript, p. 45).

Carol noticed a Best Buddies sign, her eyes brightened, she paused and then said, "I'm looking at this sign, this Best Buddies sign and I'm going, 'Nick created his own Best Buddies and he was the best man" (Transcript, p. 45).

Nick's friendliness benefited other students as well. Carol recognized that she has a "really outgoing, extraverted son" (Transcript, p. 43). She commented that "he was able not only to take his extraversion, he led his more shy classmates who didn't have good communication skills toward this more inclusive community that he himself created" (Transcript, p. 43).

I asked Carol about Nick's attending South State University at Redlands and if Desert City Public Schools' transition services had helped him find this placement. She responded No help. The transition specialist that we worked with did not tell us about this program. My husband found it online, and we contacted the school directly... [Nick] wanted to go to college and it was just amazing to us that this program was right here in Southwestern State. We've spoken to people all over the country at the Down syndrome conference and they're like, "Oh, my gosh. I'm so jealous you have that right in your state." And none of the transition people in Desert City told us about this program. We found it ourselves (Transcript, p. 42).

When I asked Carol where she thought Nick found his sense of independence, she said that she and her husband knew early on that they wanted Nick to be a "normal part of our family" (Transcript, p. 41). She underlined this attitude with an anecdote about Nick and his older brothers.

We didn't really talk about Nick being retarded. We talked early with the boys – he has Down syndrome, this you know, it does include mental retardation, and talked about the different levels that the boys are at... One day Nick was mad at his brothers and he was

running after them going, "You retards!" I just looked at my husband and I said, "What do we do with this?" (Transcript, pp. 41-42).

Carol laughed and continued to say that he was "just a normal part of the family and the neighborhood" (Transcript, p. 42).

The last question I asked Carol was what she would tell parents about high school. She thought that she might tell parents that they should ask what would be good for their children to have "as normalized school experience as possible" (Transcript, p. 43). She advised that parents find out what their child wants to do and do what they could to support that and "not let it be limited" (Transcript, p. 43). Carol further advised that in dealing with the school system parents should

Try to find out where somebody's coming from. What are their concerns? Address those concerns. Don't just say, "I've got the law behind me and this is what I want." What are the concerns and you compromise. I compromised. I had dreams of Nick being fully included all through school. I didn't push it and it worked out (Transcript, p. 44).

Carol also wanted parents not to face high school with fear. She admitted that there were things to be afraid of and told of her son's own experiences.

Our son got picked on, but you want to know something, for everyone that picked on Nick there were ten people who came to his rescue and said, "This is not happening." And they did this for other kids too...Don't listen to all the bad stuff you hear about teenagers (Transcript, p. 44).

Carol added one final remark with a warm smile and tenderness in her voice: "There are angels out there" (Transcript, p. 44).

Thomas. Theresa, Thomas's mother introduced me to Thomas. He said hello and nothing more. His speech lacked inflection and his responses were all delivered in the same unwavering tone. My conversation with Thomas occasionally became disjointed. Thomas's responses to questions were succinct and I tried to seize on his words and ask probing questions to prompt him to elaborate. While we spoke, Thomas continued to work on a textile project for an art show. He concentrated on his stitching and we had very little eye contact. In addition, there were frequent interruptions from his housemates who were doing housekeeping chores. Much of our conversation was accompanied by the sound of a vacuum.

Thomas spoke about the academic aspects of his program at Midlands High School. He remembered, "Studying ...and doing math and answering hard questions on the math problems." Later he said, "I don't remember anything that was hard for me, but PE was hard. You do exercises and everything. Get in shape and everything. That sort of stuff." I commented that he worked hard in school and asked what advice he would give to his teachers.

I would tell them that you work harder and give these students hard work and then they could do the job. Like math, science, and everything....I'd just tell the teachers that you need to give these students a hard...doing a good job and keep them on track (Transcript, p. 54).

He had told me earlier that if I were his teacher "All you can do is like help me like doing my math" (Transcript, p. 48). I asked him if there were teachers who had followed the advice he proposed. Thomas liked Mr. Fisher

Because he's..., because he likes...let us do things....Yeah, and anyway, I like doing stuff.

[Mr. Fisher] was the ...he was the woodshop teacher and stuff like that. He would let us

work on the tools and stuff like the band saw and the...the uh...other stuff (Transcript, p. 51).

When I asked him if he liked working with the band saw, he said "I would, but we did painting pieces of wood, sanding them with the sander. All kinds of stuff" (Transcript, p. 51).

Thomas also liked his Special Olympics coach. "She was nice....Well, she made me laugh. Sometimes I'd buy things from her like sweatshirts, sweaters, and sweat pants from her. She sells them and would give them for us to wear. Stuff like that" (Transcript, p. 55).

Another teacher he mentioned was "this lady that I used to go to school with. She took me on these field trips and stuff. And all kinds of stuff like the City Food Bank, and all kinds of stuff and we used to do games" (Transcript, p. 51).

He also mentioned an EA who helped him "Sort of. She tried to find me a job on school days" (Transcript, p. 56). He said the she did not find him a job after all.

Thomas spent some time as the football manager. When I asked how that had worked out for him he said, "All right. They wouldn't even pay attention to me. They wouldn't let me help" (Transcript, p. 49). He said he felt "pretty angry" (Transcript, p. 49) about that. His advice to another student who was considering managing the football team was, "Tell him, let me do it. Let me help" (Transcript, p. 49).

I asked Thomas to tell me more about his Midlands High School Special Olympics team. "Yeah. And then we just got...won competitions. State, you name it" (Transcript, p. 54). As he continued, it wasn't clear if he referred to his Special Olympics team or the school football team. He shrugged as he said, "And then we lost I remember against Bedford Hills team during the football season...Yup. And then there were like cannons that they fired up....Yup, each time the Bedford Hills team scores a touchdown....Yup, it was loud at that time" (Transcript, p. 54).

I asked Thomas about his friends in high school. He said he "did have some friends, I don't remember them very well" (Transcript, p. 47). When I asked how he spent his lunch hours, he responded, "During lunch? Just hang around with my friends" (Transcript, p. 55). I asked who he sat with; he said, "Just myself" (Transcript, p. 56). I asked what would make lunch more exciting. He replied, "When I talk to my friends and stuff. That's one thing" (Transcript, p. 56). I asked where else he encountered his friends. Thomas attended school dances. "I went to winter balls and stuff like that in the past, my high school years....It was really fun and that sort of stuff. And...um...there was a lot of people" (Transcript, pp. 52-53). He said he would "Just dance and have a good time...Yeah. there were my friends there. Yup" Transcript, p. 53).

I told Thomas that I'd like to know how teachers could help with fostering friendships. You could tell the teachers instead of....Say hey, but look there's a good person right there, you can make a good friend with them....Um...like they can.... Sometimes friends can like...like sit with you, chat with you. And you're polite to the person you want to be with (Transcript, p. 59).

He spoke of other aspects of high school. "I don't know. It's that...well, it's been really tough on me because of the high school years....Well, they've been...nervous around people and stuff like that" (Transcript, p. 47). He said that teachers could "help me to talk to people" (Transcript, p. 47).

Thomas was stitching a textile project for an art show that he said he had been working on for three months. When I asked if he had the chance to do anything like this in high school, he said, "No…because I got to learn other things" (Transcript, p. 52). The project on which he was working was part of an adult arts program.

Well City Arts Program is a place where you can sew your own art and make art there and paint, and draw, acting. You can make stuff out of clay. They hang up your art and then sell it at a really good price and then they give you part of the price (Transcript, p. 61).

He told me that he had completed an earlier project, "Oh, yeah. Like I made a quilt. I made a small one....It's about...it's a little bigger than this. Yeah" (Transcript, p. 61).

He said he would have liked high school to "last more than four years....I don't know, I just made good progress and everything," (Transcript, p. 60) but he would not want to go back to high school, "because I got other things to do" (Transcript, p. 48).

I asked Thomas what he would say to students who were still in high school. His advice: "Like, you can always, when they graduate just tell them like when you graduate you can always remember the good times and the worst times. The best times you've ever had are in high school" (Transcript, p. 57).

Theresa, Thomas's mother. Theresa's poise was obvious from the moment she introduced herself. She was dressed in a business suit and conveyed an air of confidence. She indicated a room at the front of the house where we could meet with some degree of privacy. Before we began, she noticed that I was sitting in a hard chair and expressed concern for my comfort. I assured her I was fine and asked my first question: "What were your experiences with Thomas in high school?" Her response was immediate; she laughed and commented "Not much structure there!" (Transcript, p. 63). She continued and replied that "there was positive and negative" (Transcript, p. 63). She would return to this concept again as we continued our conversation.

Theresa began by discussing the process of enrolling Thomas in the appropriate high school. Her first struggle was finding the right high school for her son. Thomas's home school was Bedford Hills, but when Theresa visited she was "pretty put off by the program. I found there was a tiny room with a handful of people who for their mainstream activity got to pick up trash after lunch" (Transcript, p. 63). She followed up this visit with an interview with an individual at the district level who validated her opinion about Bedford Hills: "Oh yeah, they like to pretend 'THOSE' people don't exist" (Transcript, p. 63) at their school.

Theresa continued her search and went on to observe at Dorothea Dix Charter School. Edward, a friend of her son's attended this school purportedly in full inclusion. Theresa "spent a day with Edward, trying to understand his experience there" (Transcript. p. 64). Theresa observed Edward in a physics class where she believed that the information was not at an "understandable level" (Transcript, p. 64). She noted that Edward's educational assistant was not with him and considered that the situation may have been different if the assistant had been present. She said, "I just found it odd and then I watched him at lunch sit all by himself, no student approached him, he was not included...and so for inclusion it just felt like a strange experience" (Transcript, p. 66). She followed up her observation with a conference with the administrators who told her that if she chose to send him to Dorothea Dix the funding he needed would take away the funds they had for a school nurse. Theresa voiced her disillusionment with such a system:

So, I'm in the position of saying OK I'll take away your school nurse by putting my kid in here... It's infuriating how people...it's just the way you feel set apart and...you're trying to do good things for your kid and you're made to feel like you're depriving people who

have all the opportunity in the world. It makes you very cynical, very distrustful of the administrations of the schools (Transcript, p. 70).

Theresa tried another approach to making a choice of high schools.

I found the largest program I could because for some reason I decided that maybe that meant they had better services and they had a wider range of population and perhaps a better attitude towards inclusion. That was really naïve because later I found out that, well, there were some cynics who said the program was large because they got extra dollars for having special ed students there (Transcript, p. 70).

Theresa found that large program and enrolled Thomas at Midlands High School. She commented that despite her hope for a meaningful experience for her son, the quality of special education services was dependent on the teachers.

Some of the individual teachers were good and some not so good. There were some where I felt he was being...it was really babysitting kind of a thing and there were other times when the teacher involved seemed like a champion and was very passionate and facile in working with differences that people have (Transcript, p. 64).

Thomas enjoyed going to school when he had teachers he liked. Theresa said that for Thomas, who had been surrounded by strong, controlling women, it was a positive experience to have Mr. Ortega. "It was nice to have a young kind of with-it guy who was interested in people with disabilities" (Transcript, p. 64). Recently Thomas ran into his teacher at the bowling alley and they "high fived and had a great conversation...It was just this wonderful conversation between two people who knew each other a few years ago and hadn't seen each other" (Transcript, p. 65).

Theresa said that Thomas enjoyed woodworking and really "latched on" (Transcript, p. 65) to the teacher, but she emphasized that success was again "teacher specific" (Transcript, p. 65). Thomas took a woodworking class every year. She laughed, "I've got more wood doodads that say 'Mom' than you've ever seen" (Transcript, p. 74).

There was another teacher who Theresa felt had done Thomas a "wonderful favor" (Transcript, p. 65). The football coach asked Thomas to be a manager. The experience was not as beneficial as they had anticipated.

Well, it worked for about two days and then it didn't work so well because Thomas wasn't very well directed. Coach needed to focus on what he needed to do so there wasn't much structure. So Thomas left to his own devices, you know, kind of stands around and doesn't really understand necessarily what he's supposed to do. Even if he's told, he just gets kind of distracted by other things (Transcript, p. 65).

It was during his time as manager that the team played a game against Bedford Hills. When they scored they shot off a cannon. Theresa said that Thomas's fear of loud noises made him panic and he "became afraid of the games and it just didn't go real well" (Transcript, p. 65). Thomas received a letter to add to his letterman's jacket and "developed at least some acquaintances" (Transcript, p. 65) and became "part of the bigger picture of football at Midlands. He's always had a lot of team spirit" (Transcript, p. 65).

Theresa described some of Thomas's other experiences with high school angst. "So in his little classes there would be the boy-girl thing and then something dramatic would happen and break his little heart" (Transcript, p. 65). When Thomas wanted to take a date to winter ball, he asked two girls who turned him down, but he persisted and got a date for the dance with a girl named Genevieve. "And she was so excited and she got her hair done and she coordinated

her dress with his tie" (Transcript, p. 66). However, teenage drama kicked in at the dance. "Almost immediately they had a fight and she was paying attention to other people and not to him and she was just a bit of a flirt....So kind of a mixed bag for his first dance" (Transcript, p. 66). They dated for a while. He admitted to his mother that they had kissed "behind the portables" (Transcript, p. 67)....He went on to describe the incident to his mother.

And this is how we do it. He said, "I put my hands around her," and he actually put his hands around me. And he said, "And that's where I touched her; that's the only place I touch her, and we kissed" (Transcript, p. 76).

As Theresa continued to talk about Thomas's dating in high school, her speech became hesitant and disjointed and she remarked that "adjustment to adolescence was difficult" (Transcript, p. 67).

She did not want to discuss some of the issues that were too private. However, she did continue to speak of Thomas's difficulty in coming to terms with his own sexuality that had serious consequences. Theresa looked into a Friendships program and tried to teach her son some of what she had learned, but found that

It was not nearly that simple and there were some pretty disturbing things that happened and he didn't understand his body changing and...um...erections, you know. He ended up in a psychiatric hospital...um...for a period of time because of all...um...the things he did to himself (Transcript, p. 67).

Theresa said that this event was "intertwined" (Transcript, p. 67) with her memories of Thomas's experiences in high school. "It's part and parcel of what was going on in his world and our world at that time" (Transcript, p. 67).

Theresa discussed the need for a program at the high school level similar to the Department of Health's friends and relationships class. She said,

I just think that such a huge part of high school experiences is understanding gender relationships, emerging sexuality that should be really addressed. Unfortunately there are a lot of parents who are uncomfortable with this [topic]...and so it falls to institutions like the education system. It's just a topic in which people need a lot of help whether they have a disability or not (Transcript, p. 68).

After a long silence, I abruptly changed the topic and asked about Thomas's classes.

Theresa said that he was in D level classes and was mainstreamed in some general education electives which she thought he enjoyed. Her voice became more somber as she said, "But you know, he didn't excel in anything. He didn't feel much gratification. I remember getting the standardized testing where your kid is zero percentile. Thank you so much Desert City School District for sending those to us" (Transcript, p. 69). There were further disappointments to follow in the graduation exercises. Thomas received a certificate different from a diploma, but he took part in the graduation ceremonies. The sadness in her voice became more apparent as she described one of the events.

And I remember at the assembly, you know, they asked the people who did this or that, these awards--stand and stay standing. You know there is this tiny group of people who are left seated and Thomas is one of them along with other special ed kids. They're sitting down. Everybody else, because everybody gets an award for something, right? And so, there's your poor child sitting there. He's sitting down (Transcript, p. 69).

I turned the recorder off at this point because both of us became emotional. When we resumed Theresa continued on the theme of award ceremonies. There had been other award and letter

assemblies at which Thomas was recognized for academic achievement, but these assemblies had been discontinued. Theresa said that according to rumor "regular ed students' parents were upset that their children's accomplishments were on a par with special ed kids...and they stopped doing the assemblies as a result...So one of the ways he got recognition was taken away" (Transcript, p. 70).

I asked Theresa about Thomas's IEPs. Without hesitation she remarked "Loooong. Lots of paper. Not a sense of accomplishing anything at all. Rote process. Needed to show people you're doing something. But not a real sense of progress or really measurements" (Transcript, p. 70).

In her unique position as Thomas's mother, unlike other members of the IEP team,
Theresa recognized Thomas's capabilities.

He has a really high visual memory...He has a visual map of the city. I mean the bus system was like this [snaps her fingers]. And he'll make changes and he'll be out and he'll call me, "Mom, I think I'm going to take the number two or the number three [Laughter] and stop at Hastings." And I'm "OK. It's all cool" (Transcript, p. 73).

She described an incident in his doctor's office when Thomas demonstrated that he understood more than even she thought he did. He was able to restate specific and complex discussions between his doctor and his mother about titrating medicines and increasing his exercise regimen.

She elaborated about the inconsistencies in their IEP meetings. "Felt like every time we turn around different people would show up and a different teacher. You know, maybe the nurse would come, maybe not. It was just very disjointed" (Transcript, p. 71). Theresa also spoke about the lack of continuity in Thomas's' support teachers from year to year. "It was whoever the teacher was for that year, his main homeroom teacher" (Transcript, p. 74). Theresa

said that the effectiveness of teaching "Again, depended on the individual. Some were babysitting and some were probably getting more done with him...just hit and miss and then they'd leave" (Transcript, p. 74).

Theresa compared this experience with the current support team that is working with Thomas. Her use of the plural form indicated that she was part of a team and not operating from an isolated stance.

We've become really functional and effective because we have a circle that's been very stable and we can be pretty efficient and we know what we're talking about now....It's been this gradual building process over years, thanks to this stable case manager and then as we added people who were also sort of in there for the long haul that we felt compatible with. It's like continuity of care. You need these people who talk the same talk and kind of understand him, his history and can put it together (Transcript, p. 70). She commented that the members of Thomas's group home house staff have been added to the team and are "of that same mind" (Transcript, p. 71).

Being a member of a group home and being involved in new and many activities changed Thomas's relationship with his friends. Edward, his best friend, used to visit Thomas and stay for a sleepover. Theresa added that since Thomas is "not in my house, it's just not happening" (Transcript, p. 72). Theresa also said that getting the boys together now has been "harder to coordinate logistically and Edward's just a busy guy and Thomas has been a busy guy" (Transcript, p. 72).

Other friendships developed in elementary school and middle school. Theresa said there were not a lot of close friends and "He lost one of his close friends in the transition from middle

school to high school....They grew apart and when they went to different high schools that really exacerbated that' (Transcript, p. 72). Moving on from high school brought on further losses.

Friendships – that is one of the tragedies of graduation and transition – you lose the built in network of people who were there who you would call your friends, even though, I don't know if you really had that kind of relationship with people you hung out with every day, went to your classes with every day (Transcript, p. 73).

Theresa commented that Thomas "was more comfortable with adults than he is with his peers. He has a lot of adult interactions, so not a lot of close friends" (Transcript, p. 72). She added that his experience in the group home with other adults has been good for him because "he has his roommates to relate to" (Transcript, p. 72).

I asked Theresa about transition after high school. When I asked about what help she received from the district she replied, "I remember going to that transition fair a couple of times and just walking around and going, "What the hell is that?" (Transcript, p. 73). There was some mention of postsecondary programs at IEP meetings, but generally, Theresa didn't see that she received much help from school administration. She found that "parents were probably one of my biggest resources...Especially during Special Olympics events, we'd stand on the bleachers. 'Hey how do you...?" (Transcript, p. 71). One piece of information that Theresa believed was vital was applying for the DD waiver. She said she found out about it accidentally. She also mentioned parents who did not hear of the waiver until their child was twelve, and the waiting list at that time was 8 years.

And you know the waiver is [Sigh] is...is...it's just got to stay. I mean it's the one thing that really, as a single parent in particular, I couldn't have done; I couldn't have taken

care of my family...without the waiver there to help support him and me. And I hate to say it but a lot of the professionals in the school system – not so much...

It's like trying to find the collective knowledge that wasn't in the school system....

There needs to be some kind of portal for parents and families with kids with intellectual disabilities where you can go and it connects all the resources for your area...There's no systematic way for parents to find resources...There's no resource that helps you sort through the crap.

You know when you start you don't have any idea what the path is and what to ask for... You know, you need a sort of global resource place to go to because you're busy dealing with whatever you're dealing with.

In Thomas's case, he was very ill as a child and it was just trying to get him through another day. You don't have time to research and you need, you know, a place to that helps you sort through. Call it a portal.

If policy makers want to know, that's what we need. We need that quoteunquote institution that provides us answers, resources to help our children because we are their best advocates. We know them and we care for them, you know, and with a little help we'll figure it out but we need to understand (Transcript, pp. 74-76).

In this chapter I presented the results of my research in the form of individual portraits based on the interviews I conducted with the participants. I intended each portrait to represent the unique point of view of each individual as well as to allow each participant's voice to be heard clearly.

## Chapter 5

## **Data Analysis**

This chapter includes an analysis of the commonalities of experience among the participants, beginning with those of the former students and moving on to those of their mothers and, in David's case, his older sister. These analyses are followed by interpretations of the individual portraits to look for insights and explanations of the experiences of the participants.

Data were collected through semi-structured interviews with former students with disabilities and their family members. I examined the interviews – both audio recordings and transcripts – to identify any themes that might help to capture any convergences among the participants. A preliminary overview of the transcripts revealed some areas in which the participants' stories reflected similar experiences. These areas of convergence became more apparent in the final portraits of each participant and coalesced into threads that ran through the interviews. However, because each interview was unique, my analysis included experiences that were specific to each individual. I sought to "capture examples of convergence and divergence, rather than focusing solely on commonalities" (Pringle, Drummond, McLafferty & Hendry, 2011, p. 22). In order to assure that the participants' voices were clearly reported in the study, I created a portrait of each participant to capture their experiences and their identity, which, according to Smith (2004) "emerges as a key organizing principle" (p.49).

## **Common Threads**

The former students. The three young men were all placed in predominantly small group, special education classes with a few general education electives. Not one of them was included in general education core classes, viz. math, English, science, social studies. All of them,

however, had social interaction to a greater or lesser degree with the general education population.

Although not all of their experiences were positive, all three young men expressed that they liked school. David said it was "AOK. It was fine" (Transcript, p. 2). Nick said, "High school is awesome" (Transcript, p. 26). Thomas stated at one point that he would have liked high school "to last more than four years" (Transcript, p. 60). David and Thomas's statements were in contrast to some of the negative events in their high school experiences; yet, their overall memory of their time there was positive.

As a researcher I need to consider that these young men presented an impression of their schooling that might have been couched in language to appease me. Despite my efforts to establish myself as non-authoritative, there is the possibility that I was perceived to be an authority figure in my role as interviewer. Edgerton (1993) claimed that individuals can alter the stories of their lives in order to "embellish" their experiences (p. 226). In discussing the behaviors of individuals with intellectual disability in their involvement with the judicial system, Ellis and Luckasson (1985) asserted that "many people with mental retardation are predisposed to 'biased responding' or answering in the affirmative questions regarding behaviors they believe are desirable" (p. 428). Perske (1991) presented a series of cases within the criminal justice system in which defendants with disabilities were embroiled in a system from which they could not escape because of their initial acquiescence with investigators.

One explanation for David and Nick's positive memories may lie in their personalities.

David and Nick were personable and amiable in their conversations with me. Both young men presented their pleasant experiences with enthusiasm and spirit. Their voices rose and their

demeanor became more animated. Nick's memories, with the exception of one minor incident with an educational assistant, were all pleasant.

Thomas presented a more flat affect. He recalled experiences both positive and negative in the same tone and with no change in body language. Yet he still offered advice to future students that "The best times you've ever had are in high school" (Transcript, p. 57).

Although their stories abounded with memories of social interactions, all three young men spoke of their respect for the academic purposes of high school. David said he "knew what school was and took it seriously" (Transcript, p. 7). Nick expressed that good teaching included "math and learning how to read and stuff" (Transcript, p. 32). Thomas remembered "studying and doing math" (Transcript, p. 46). In one form or another during his conversation, each young man made reference to math. David spoke of the usual pattern of field trips that included counting zebras and monkeys. Nick said that teachers should teach him math, and Thomas remembered "answering hard questions on the math problems" (Transcript, p. 46). The attitude of these young men reflects their understanding that their education is a significant part of their lives.

A third point of convergence among David, Nick, and Thomas was their bonding with particular teachers. David's experience was exceptional in that his favorite teacher was his sister during his last year of high school. Nick developed a relationship with his PE teacher who became his Special Olympics coach. And Thomas spent a great deal of time with his shop teacher. Though each former student's personality differed greatly from the others', each young man gravitated toward a teacher who suited his distinct traits and was able to enhance his high school experience.

A summary of topics common to the young men can be found in Table 2.

Table 2. Comparison and contrast of former students' experiences

Experiences	David	Nick	Thomas
Postsecondary	Living with family and looking for job	Living with family and specialized 4- year college program	Group home and city arts program
Advice to teachers	Treat students with respect and not mean	Teach what we should learn in college	Give students hard work and keep them on track
Self-awareness/Self-determination/Self-advocacy	Acutely aware of his particular difficulties in school. Recognizes his employability skills. Expresses need to put problems behind him	Spoke with principal to remove an EA who did not treat him right. Advocated for his right to leave campus as a senior	Enjoys self- expression in arts and crafts projects in City Arts Program
Enjoyed non-academic aspects of school	Field trips and being cheerleading manager	Participated in student council activities	In woodshop he liked the band saw and painting and sanding pieces of wood.  Managed football team for a short while
Reliance on adults	Spent time in school office with personnel Joined his sister's class where she could supervise him	Spoke up for himself to get what he needed from administration	Spent time with wood shop teacher
Personable/Ease of conversation	Polite, straightforward and friendly	Polite, animated and warm	Lack of eye contact/Minimal responses
Positive outlook	School was A-OK. Confident about finding a suitable job	Found high school "awesome." Confident in his job as a successful manager of his own business	Said he made good progress in high school Interested in arts and crafts in post- secondary city program

Experiences	David	Nick	Thomas
Involvement with Special Olympics	No involvement	Involved in setting up and participating in a school-based team. Continued after high school as a global messenger	Member of school- based team and won competitions
Importance of particular/special teacher	His sister during his final year of high school	Mentioned that two teachers were special because they helped him.	Special Olympics coach and wood shop teacher
Desire to be like other students	Perhaps implied in his enjoyment of cheerleading activities	Actions to leave campus with the other seniors because he wanted to hang out with his friends	Stated that other students did not pay attention to him when he managed the football team

The mothers and David's sister. In each case, the former student's parent who participated was his mother. It became apparent that family support, spearheaded by their mothers, helped sustain the young men's progress toward independence and success.

All three mothers and Nick's sister indicated that the quality of education was, in Theresa's words "teacher specific" (Transcript, p. 65). Each mother described positive and negative experiences with her son's teachers. Each parent cited specific experiences which were unhelpful and, in some cases, harmful for her son. Kate described some of David's classes as "a disaster" (Transcript, p. 15); Carol observed one of Nick's classes in which the students watched movies and the teacher was "just counting the minutes" (Transcript, p. 41); and Theresa said that some of Thomas's classes were really "babysitting" (Transcript, p. 64). Meghan, David's sister commented that schools "just couldn't get it" (Transcript, p. 22). Their

observations call the quality of teachers in the school district into question. That raises the issue the practice of placing students with teachers who do not meet the standards expected of qualified teachers.

The parents also spoke about positive experiences with teachers whose skills and concern for their sons provided benefit and enhanced their high school experiences. Kate mentioned a "seasoned teacher" (Transcript, p. 17) who was good for her son. Carol had high praise for Nick's Adaptive PE coach who transformed her PE program to create a Special Olympics school team. Theresa talked about a positive experience that Thomas had with a "young kind of with it guy who was interested in people with disabilities" (Transcript, p. 64). The mothers recognized that talented teachers can make a difference and, in a way, counteract the sometimes lackluster methods of inexperienced or uninterested teachers.

There was a consensus among the mothers about the value of the IEP and IEP meetings – that they were virtually insignificant in their sons' education. Kate said that David's IEPs "always sound better than what the reality is" (Transcript, p. 14). Carol had misgivings about the supposed individualization of IEPs and that rather than being for the benefit of her son, Nick, they would just "go through the motions" (Transcript, p. 37). Theresa's impression of Thomas's IEPs was that they were a "rote process" (Transcript, p. 70) with no "sense of accomplishing anything at all" (Transcript p. 70). The IEP meeting and the documents that ensue are meant to ensure the individualization of the instruction of each student. The mothers' evaluations of the process did not support such individualization for their sons.

Another area on which the parents agreed was the lack of meaningful transition services to postsecondary education or employment. Kate stated that she thought that the district had "dropped the ball" (Transcript, p. 19) by placing David in a job without the support he needed.

David's sister commented that they were working with job developers who "don't seem as motivated as they should be" (Transcript, p. 24) and that his family was helping him on their own. Carol commented that the transition specialist they worked with did not help them. This lack of assistance was underlined by the fact that Nick's family found an exceptional postsecondary placement in their home state – on their own. Carol said that the transition specialist "did not tell us about this program" (Transcript, p. 42). According to Theresa, the sum total of the help that she received from the district was a transition fair; she relied on parent contacts as "resources" (Transcript, p. 76). IDEA calls for meaningful transition for students with disabilities. These mothers indicated a gross violation of this tenet as it applied to their sons.

Besides the common threads that ran through the experiences of the young men and their mothers, the essence of their experiences is best expressed in their individual stories. Each participant had a unique story to tell.

## **Individual Experiences**

David, Kate, and Meghan. David demonstrated a remarkable self awareness, both in recognizing the difficulties he encountered and in understanding his maturation and his ability to enter an adult world. He commented on the lack of skills that made his ditching classes fruitless: he could not venture off campus to buy something because he didn't know "how to count change" (Transcript, p. 7). He openly discussed the anxiety (later clarified by his family as psychosis) as a factor in a memorable IEP meeting. He followed this discussion by expressing his understanding that he now had control over his behavior, that he knew these problems were in the past and that he had to "leave it alone" (Transcript, p. 6). David seemed confident in the skills he could offer an employer. He said he was "very professional on the phone" (Transcript,

p. 12). This was easy to accept as fact given the clarity of speech and the ease of conversation that he demonstrated when we met.

David adopted a serious attitude about school, recognizing its importance and wanting to be accepted as a good student. He said that he "went with the flow" (Transcript, p. 7) that he knew "what school was and took it seriously" (Transcript, p. 7). In his story about a student, likely himself, who was always on time and "didn't give the teachers any problems," (Transcript, p. 1) David recognized the authority of his teachers and administrators in high school. Perhaps to maintain the image of a good student, he tried to avoid the consequences that he would incur if he did not follow the rules, at times hiding in the rest room when he ditched classes.

David seemed willing to cut high school programs and procedures some slack. He said that school was "fine...it was the best thing" (Transcript, p. 2). He was enthusiastic about field trips that were "fun and educational" (Transcript, p. 6). He said his teachers were "never mean" (Transcript, p. 6). He even described his IEP meetings as being good, despite a negative experience in which they didn't ask him about his anxiety but "just said in the IEP" (Transcript, p. 5).

Kate, David's mother presented a different picture of his high school years, beginning with the difficulty she had in finding a placement that suited his needs and his personality. The schools "didn't want to" (Transcript, p. 14) place him in general education classes, except for a few electives. He was placed in "D" level classes where he encountered behaviors that were offensive to him. He was later placed in CRL classes. Although she considered these a better fit, she found the lessons were not suitable for David's needs. All in all she was never "really thrilled" (Transcript, p. 14) with any of his classes.

In contrast to David's positive assessment of high school, Kate presented a generally negative view of David's experiences. Even so, similarly to David, Kate was willing to cut the schools some slack. She offered excuses for a teacher who was ineffective for David; she assessed her as being "just new and green" (Transcript, p. 17). This sympathy may have originated in the difficulties that were inherent in her own first years of teaching. She criticized general education teachers for not welcoming David into their classes, but also excused their behavior because they had "a lot of students with a lot of grading" (Transcript, p. 18). She described David as "more of a social guy," (Transcript, p. 15) and commented that his teachers did not give him opportunities to increase his social interactions or to become part of a peer buddy program. She also asserted that the IEP process and transition services were not supportive of David's needs. Meghan, David's sister underlined the failure of the system to include David when she said that "they just couldn't get it" (Transcript, p. 22).

The question arises then, that despite her disappointment with her son's education, why did she keep him in the school system until he was 22. Kate indicated the overwhelming nature of the system that controls education when she admitted that "you get confused" (Transcript, p. 20). It is a sad comment that her hopes were frustrated by a system in which "the reality is never as good as the fantasy" (Transcript, p. 14).

David's personality, apparent in his words and his demeanor, indicated that, according to research, he is a student whose inclusion in general education could be accommodated. In David's case, however, he was excluded on a permanent basis.

**Nick and Carol.** Nick exuded confidence and charm. He spoke with spirit, especially when he told stories about his success. Other than a minor incident with an educational

assistant, his assessment of high school was consistently positive. His exuberance colored almost all his reminiscences.

Nick's experience was not typical of most students with intellectual disability. In fact, some of his experiences are not typical of most high school students, with or without disabilities. Very few have the honor of being elected homecoming king or being invited to Cancun to be best man at a friend's wedding or receiving a ten-minute standing ovation at an assembly. An overview of his accomplishments revealed that a good portion of the accolades he received were the result of the support of his peers. He expressed this eloquently when he said, "All my friends love me 'cause I'm like part of everybody in the world" (Transcript, p. 32).

Nick's self-assurance served him well in high school. He advocated for his own needs speaking directly to the principal in order to leave campus with his friends in 12<sup>th</sup> grade and talking to a teacher to have a bothersome EA removed from his class. Again, this is not typical behavior of most high school students in special or general education. He topped off his high school experiences with a four-year specialized program at a state university; involvement with Special Olympics as a global messenger; and an enviable career as a successful business owner. Taking Nick's recollection of high school at face value presents a picture of contentment and unimpeded progress. According to Nick, high school was a place where he "had the whole school as [his] backup" (Transcript, p. 25).

Carol, Nick's mother emphasized also the positive aspects of Nick's high school years; however, she included the trials and difficulties they encountered in dealing with the bureaucracy that regulated special education. Carol confirmed the positive effects of Nick's self determination and outgoing personality. She referred to Nick's resolve in securing permission to join his senior classmates off-campus during lunch. She attributed his decision to run for

homecoming king to that same determination that he demonstrated in advocating for himself. She underscored the essential role that the students played in helping Nick achieve his goals. She complemented the story of Nick's role as best man at his friends wedding by noting the influence his open offer of friendship had on the groom, inspiring him to designate all the male members of the wedding party as "best men" (Transcript, p. 45). Carol noted that Nick made the best of riding in the special education bus and being a member of small group classes by helping his classmates who were shy become part of a larger inclusive community.

When she assessed the services that Nick received at Cortez, she extolled the virtues of the speech and language pathologists and the adaptive PE teacher who developed programs that were beneficial for her son. She was pleased with the community based instruction that Nick received in ninth and tenth grades that helped him develop skills to enable him eventually to live on his own.

Unlike Nick, however, Carol did not believe that there were no negative aspects of his high school education, especially during his eleventh and twelfth grade years. She recalled that the community based instruction he received in his first two years of high school did not continue and she expressed displeasure with his teacher. When she spoke of Nick's IEPs she recognized that they were not truly individualized for Nick and that they served a purpose for the bureaucracy of the system and not for the needs of her son. Carol admitted that by the time Nick reached high school, she was tired and not as eager to fight for inclusion at the administrative level. She and her husband would just "go along" (Transcript, p. 37) with the IEP and then took over the tasks themselves of working with Nick's individual teachers.

Despite the failures of the educational system, including not helping Nick's family find a postsecondary educational placement in their home state, Nick is a productive member of the

larger society. Carol credited his burgeoning independence on his being "just a normal part of the family and the neighborhood" (Transcript, p. 42). Nick's family apparently understood the importance the principle of normalization by encouraging Nick to experience the "patterns of life and conditions of everyday living which are as close as possible to the regular circumstances of life and society" (Nirje, 1976, p. 231).

Nick's family worked around the bureaucracy. They were able to provide Nick with benefits denied him by administration. They worked independently with individual teachers and encouraged his relationships with his peers. Nick's family assured that he was accepted and welcomed into his school community, his neighborhood, and the social and business community of his home city.

Thomas and Theresa. Thomas was more of an enigma than the other two young men. It was difficult for me to draw him out. As we talked he concentrated intently on his needlework project. Sometimes his answers were contradictory. He said that he didn't remember that "anything that was hard," (Transcript, p. 52) but then followed with the assertion that "PE was hard" (Transcript, p. 52). He mentioned using the band saw in woodshop, but then implied that he did not use it but instead painted and sanded. He said that being the football manager was "all right," (Transcript, p. 50) but then followed by describing his lack of interaction with the other students that made him "pretty angry" (Transcript, p. 50). He said he had lunch with his friends, but then followed by saying he sat by himself.

Thomas was insistent that school was for hard work; his recollection of school was of studying and doing math, "answering hard questions on the math problems" (Transcript, p. 48). He advised teachers to give their students hard work and keep them on track. In response to my question of what I could do for him as a teacher, he told me that I could help him with his math.

Referring to the current art project he was working on, I asked if he had done similar projects in high school. His response was that he had to "learn other things" (Transcript, p. 52). Yet his memories of specific aspects of high school were of non-academic elements: painting and sanding projects in wood shop; buying sports paraphernalia from the Special Olympics coach; field trips to the local food bank; and attending winter ball and other dances.

Although Thomas did not explicitly bemoan the lack of friends, he ate lunch by himself. He said that he had a good time at dances with his friends, but later implied that he was nervous around people and that teachers could have helped alleviate that anxiety. His remarks about how teachers could help him nurture friends were poignant – that teachers could point out that he was a good person and let other students know that they could chat with him. Teachers could have helped him "talk to people" (Transcript, p. 47).

Thomas's poor communication skills served to isolate him from his peers. He offered little resistance to the practice of segregating students with disabilities from the general population. His general anxiety, although detrimental to him, was beneficial for a system that appeared to have ease of administration and control as its goal. Thomas's disability not only isolated him, but also made him more susceptible to the structures in the school that served the needs of the system rather than the needs of an individual student, especially one who acquiesced so easily.

The longest and most intense conversation I had was with Theresa, Thomas's mother. She understood both the vulnerable nature of her son and the inflexible constraints in the structure of the school system. Her visit to Bedford Hills High School and her subsequent conversation with district personnel must have made a dreadful first impression of the treatment of students with intellectual disability in the school district. Her observations at a district charter

school provided confirmation that the term "inclusion" belied the reality of integration of students with disabilities in the general population in district high schools. In addition, being told that acceptance of her son would mean that other students would lose health services presented her with a catch-22 dilemma. She expressed cynicism and distrust in a system that would place a parent of a child with a disability in such a predicament.

Theresa chose to enroll Thomas in a school that had a large special education population, hoping that the more extensive program would offer her son more opportunities to be included with the whole school community. He was included in some general education electives, but his placement was primarily in small group, special education, "D" level classes. "D" level does not refer to the abilities of the students but rather to the funding level provided by the state. In such classes the teacher to student ratio is typically eight to one or better. In these classes one would expect that students would receive individualized attention and be able to make good progress. However, Thomas's experience in those classes contradicted this expectation. Theresa displayed sadness when she commented that Thomas did not "excel in anything," (Transcript, p. 69) and that he "didn't feel much gratification" (Transcript, p. 69). Her son's failure to make adequate progress was underlined by the insensitivity of the district in sending home his zero percentile standardized test scores. This disappointment was temporarily offset by Thomas's recognition at school wide awards assemblies; however, this practice was discontinued at his high school so that he lost the opportunity to be acknowledged in front of the student body. Theresa's cynicism came to the fore when she attributed the loss of the awards assembly to parents of general education students who felt that rewarding special education students diminished the value of the awards received by their sons and daughters.

Theresa was dismayed by what appeared to her to be a callous action on the part of the school administration. At the graduation honors assembly, a ceremony that all graduating seniors are required to attend, students who receive any honors are asked to stand and remain standing until all students on the list have been recognized. Theresa pointed out that the few students who remained seated are easily singled out as students with disabilities, including her son.

Theresa acknowledged that Thomas's teachers ran the gamut from babysitters to champions. She did not linger on her assessment of ineffective teachers. Instead she offered praise for those teachers who had made a difference in Thomas's education. She specifically cited a young, "with-it guy" (Transcript, p. 64) and a woodworking teacher whose class Thomas took every year. Although Thomas had a less than successful experience as manager of the football team, Theresa was grateful that the football coach gave him that opportunity. The relative effectiveness of his teachers was also an issue in his IEP meetings. An additional obstacle to a meaningful education for Thomas was the inconsistency of support teachers from year to year that resulted in IEP meetings that were "disjointed" (Transcript, p. 71). This differed greatly from the "continuity of care" (Transcript, p. 70) that was in effect in his current situation where Thomas's welfare is coordinated within a team, of which Theresa is a vital member. Theresa's further comments on Thomas's IEPs revealed that she believed they were "rote" (Transcript, p. 70) and involved a great deal of paperwork that she felt was needed to show that the school was "doing something" (Transcript, p. 70). They were not relevant to Thomas's abilities. The IEP meetings included some mention of postsecondary programs, but in general, they received little help beyond transition fairs in accessing services after high school.

Theresa's innate wisdom encouraged her to use other sources for gathering the information she needed. She specifically mentioned the value of parents as resources for other

parents. Theresa stated that she acquired information about the Developmental Disability (DD) Waiver "through an accident" (Transcript, p.75). The DD Waiver is a program that provides needed services for individuals with developmental disabilities, including medical assistance, case management, and transition services. She expressed how important this was as a support for Thomas and her. Theresa described her ideas for a system that she called a portal that would be a resource for all parents of children with disabilities who needed to find the help and services that they need. She was passionate when she spoke of parent's inability to conduct research into resources because often they are struggling just to get through each day.

Theresa spoke with great tenderness about her son's individual experiences, including the loss of friends that resulted from changing schools, especially in the transition from middle school to high school. She spoke of conflicts that would "break his little heart" (Transcript, p. 65). She described in detail how he explained how he had kissed a girl "behind the portables" (Transcript, p. 67). Stemming from this description of an innocent interchange between Thomas and a girl was Theresa's deep concern for the need for sex education in school. She spoke very briefly about difficulties that Thomas had in coping with his emerging sexuality and the resulting admission to a psychiatric facility. She described her personal campaign to find a program to help her son find a way to understand the nature of gender relationships. She is a strong proponent of school based programs that help students adjust to adolescence, including burgeoning sexuality.

Theresa reached beyond her affection for Thomas and expressed concern over the quality of a system that did not serve the needs of students with intellectual disability. Many of her experiences and her observations were applicable to other students as well as to her son. The relationships program she recommended, the request for access to information, her

acknowledgment that students with disabilities did not receive the recognition they deserved, and her understanding of the difficulty for making friends – these concerns provide a roadmap of sorts that might lead to improvements in the special education system.

### **Positive Signs**

Despite the overall impression of a system that does not serve the needs of its shareholders, it is important to note that there is room for optimism. The experiences of each family included stories of success within the system. Each former student found a teacher who was willing to go beyond expectations in order to help him make progress and be accepted. David found a counselor who offered him the opportunity to volunteer, allowing him to be in the role of a giver rather than a receiver of help. Kate singled out a "seasoned" (Transcript, p. 17) teacher who taught David about issues that she believed were important to David's growth. Probably one of the brightest lights that came through was the role of David's sister, not only as his teacher, but also as an advocate for students with disabilities.

It was difficult to find examples of positive experiences in Thomas's story. Part of that difficulty may lie in Thomas's flat affect. He wanted to tell future students, "The best time you've ever had are in high school," (Transcript, p. 57) but he didn't offer specific instances that would make this true for him.

Theresa was able to find an individual at the district level to listen to her and support her reasons for rejecting Thomas's home school as an appropriate place to enroll him. She singled out two teachers who made a difference for Thomas, and mentioned that there were teachers who were "champions" and who were passionate about their work with students with disabilities.

The brightest beacon of optimism was presented by Nick and his mother, both of whom had faith in the inherent goodness of high school students. Nick's story presented the innate goodness of young people, a fact often overlooked by those who see teenagers portrayed at worst, as villains and, at best, troublemakers. Some members of the general public do not see that teens are capable of affection and compassion for their peers. Nick had the whole football team to support him against the fools who would bully him. He developed a long term friendship with a young woman who included him in her wedding party. The entire student body recognized his achievements in Special Olympics. He was elected homecoming king. Nick summed up his relationships with his peers: "All my friends love me 'cause I'm like part of the world."

Carol, Nick's mother, found support and beneficial advice from one of Nick's special education teachers. She also had high praise for his speech language specialists. Carol underscored the role of Nick's peers in welcoming him into their circle of friends. She advised parents not to pay attention to the misleading image of teenagers but instead to embrace the generous hearts that they possessed. Her closing remark sums up the reality of a benevolent school community: "There are angels out there."

In this chapter I looked at the data to discover commonalities and areas of divergence among the participants' reports of high school experiences. I also attempted to look for explanations of their experiences and to arrive at insights into their recollections of their high school years.

# Chapter 6

#### Discussion

The cord that binds the individual stories of the former students and their families is their eventual concession to the power of the bureaucracy that determined placement, services, teacher quality and adherence to the law. According to Vaandering (2010), "Dominant power structures are a reality in Western democratic societies" (p. 172). The responses and attitudes of the families indicated a resignation to the inevitable.

We are informed by the individual stories that teachers should recognize that the students and families whom we serve are not homogenous and should not be subject to one-size-fits-all practices (Meier, 2004). Although there were some experiences that were similar among the participants, the unique experience of each of them expresses diversity that overshadows the common practice of merely assigning them to a disaggregated group in order to report standardized test scores. What is being lost in the current climate of education is the individual student, especially the student with intellectual disability. Standardizing education does not mean improving education – it means reducing our students to data that can be used for political purposes. Danforth (2008) eloquently explained how Dewey viewed the value of standardization.

Given that different purposes or outcomes would require different standards of evaluation, it struck Dewey as illogical that one test could conduct a universal scale of value that somehow applied to all life's contexts and goals. Additionally, he noted that... a test that demonstrates the superiority of one over another is merely failing to evaluate the actual life activities engaged in by the supposedly inferior groups... Dewey's purpose is larger than the deflating of nomothetic concepts of superior or inferior. His target is

the old undemocratic habit of scaling persons on a value axis from top to bottom, worthy to unworthy, more than equal to less than equal (p. 49).

Theresa highlighted the distressing effect that ranking students can have on the students and families when she "thanked" the district for notifying her of her son's zero percentile score. That score does not reflect the individual reality of Thomas and does not even provide useful information to design an educational plan. Subjecting students to classifications that indicate inferior status strengthens the power of the dominant culture and reifies the class system that keeps individuals with disabilities at a social disadvantage.

### **Legal Considerations**

In reading the stories of David, Nick, and Thomas, we see three distinct personalities with individual patterns of behavior. Their only common characteristic is their designation of intellectual disability. David expressed an uncanny understanding of his own personal and social growth; Nick demonstrated a remarkable urbanity that serves him well in running a business; and Thomas exhibited an introversion that inhibited facile conversation and belied his desire to form friendships. The high schools that they attended placed the three of these young men in segregated settings. Their inclusion in the general education community – even in a limited capacity – was orchestrated through their own determination or the intervention of their parents. How is this justified in light of the language of IDEA?

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of

supplementary aids and services cannot be achieved satisfactorily (20 USC 1412 Sec. 612 (a)(5)(A)).

Neither the young men nor their parents were offered the option to be included in general education "with the use of supplementary aids and services." The parents' discussions of IEP meetings did not include the offer of providing a free and appropriate public education (FAPE) in general education nor did they mention the compelling reasons offered by the schools to remove their sons from general education. They emphasized the perfunctory nature of the meetings and the resulting documents.

Despite the guarantees from the federal statute, it appears that control resides in the amorphous systems that define education, including special education. Despite their dissatisfaction with the special education process, not one of the parents mentioned invoking their right to due process. The parents in this study did not challenge the status quo or invoke their rights granted by IDEA. Kate did not want to make people mad; Carol just went along with the IEP; and Theresa said that the IEPs did not accomplish anything. They "adapt to the purposes which the dominant minority prescribe for them thereby depriving them of the right to their own purposes" (Freire, 2000, p. 76). Institutions can exert consistent and subtle pressure on parents to accept what is offered instead of what they deserve.

#### The Role of Teachers

Although special education teachers are included on committees and instructional councils, their ability to change the system meets with insurmountable obstacles. Decisions are made at higher levels and teachers' future employment is dependent on their compliance, and that compliance has been reduced to raising test scores.

It should not be news to anyone that teachers across the country, either by choice of in response to administrative pressure, are teaching to the tests. Why shouldn't they? When test scores are all that matters...test preparation is the order of the day....Teachers across the map complain that the joy is being drained from teaching (Wood, 2004, pp. 38-39).

In the current climate, teachers' voices have been silenced and their expertise disparaged. Much like the parents in this study, good special education teachers are resigned to accept the constraints of the system and to work outside the system to serve their students and provide them meaningful education in the least restrictive environment. Meghan, David's sister provided an example of this resistance; her actions indicated her understanding of the "momentous role that teachers play" (Keaney, 2012, p. 849). She accepted her assignment to a segregated class and worked under the radar to find ways to include her students in general education classes.

Inexperienced teachers and those less qualified accept the mandates of the system and follow the pattern that causes the least resistance, much to the disservice of students with disabilities; thus, the common experience of the parents as expressed by Theresa that success was "teacher specific."

Although the mothers did not refer directly to teachers' attitudes, their understanding of the role of those attitudes in the education of their sons is implied. Kate spoke of a teacher who had her own issues that impeded her work with David. She also clearly expressed the value that general education teachers should be welcoming of students with intellectual disability like her son. "The success of any integration effort is crucially dependent on the willingness and capacity of our teachers to implement it" (Keaney, 2012, p. 831). Carol mentioned the defensive stance of school personnel at their IEP meetings and commented on a teacher who was "just counting the minutes." Theresa was clear about her perception of the attitudes exhibited in certain

schools, including one where she was warned that they believed "Those people don't exist." This exclusionary attitude was also expressed in a charter school that made her feel as if she would be "depriving people who had all the opportunity in the world" if she chose to enroll her son. Such a negative institutional position became apparent at Thomas's home school as well as in the elimination of academic awards at assemblies and the visual exclusion of students with disabilities at the honors assembly during graduation exercises. Students are subjected daily to the actions of their teachers and administrators who can either accept or reject principles of inclusion. They are fortunate if they are assigned to teachers who are passionate about teaching and are the "champions" that Theresa mentioned.

I believe that the current political and executive oppression of education requires special education teachers to become subversive in order to resist what they believe is harmful to their students and to recognize that "oppressive conditions always produce resistance" (Leonardo, 2004, p.16). Teachers, whose livelihood depends on the vagaries of school boards and departments of education, still have the obligation to meet the needs of the students whom they serve. Bold defiance of the status quo jeopardizes the position of teachers. With the current denigration of the profession and the apparent incapacity of teachers' unions to take effective action, teachers are left with the unenviable options of either acceding to systemic control or offering the appearance of compliance while using their skills and expertise to educate their students effectively. This choice is inevitably a crisis of conscience.

The National Board for Professional Teaching Standards sets goals for accomplished teachers. Among their standards for teachers of special needs students is an expectation that special education teachers become advocates for their students and their families.

Accomplished teachers comply with the laws and understand their advocacy role in safeguarding the due process rights of students and families in decisions about assessment, placement, instruction, and transition. Teachers recognize their responsibility to ensure to the best of their ability that everyone involved in educating students with exceptional needs is informed about legal mandates that protect student and family rights....Teachers advocate for students to have meaningful access to the general curriculum, appropriate learning opportunities, and related activities. In some cases, these teachers challenge the philosophy and educational delivery system of the school, the district, or the service agency and advocate for changes to meet the needs of students and their families. (NBPTS, 2010, p.31)

# Implications for Teacher Preparation

Teacher preparation programs in special education should include a clear and thorough understanding of the law governing students with disabilities. Teacher candidates, especially those in special education, should be knowledgeable of the laws that affect their students and their families. Even a cursory perusal of IDEA will inform them of the requirements to place students in the least restrictive environment, include families in decision making, and individualize education programs for students with disabilities. Knowledge of the law will provide them with a platform for developing appropriate educational environments and strengthen their voices in situations that challenge the rights of their students. The experiences of the participants in this study might have been different if teachers, who knew that they had the strength of the law behind them, were comfortable in insisting that administration abide by the principles of IDEA.

Teacher preparation programs are faced with the dilemma of preparing potential teachers for the reality of the restricted systems into which they will enter or engaging them in the development of creative and effective teaching methods. I am dually certified in special and general education. In my practice as a high school teacher, I have tried innumerable methods, challenged conventional wisdom, provoked controversy, and developed successful curriculum and supported student success for both general education and special education students. In line with the philosophy of the university in which I teach, I bring my experiences and my learning to the teacher preparation classes. However, I know that I have the status of a veteran teacher and can challenge the status quo with confidence. I question whether or not I should encourage beginning teachers to tread such a treacherous path – possibly jeopardizing their positions in school systems that require compliance to bureaucratic restrictions. At the same time, I believe that preparing teachers should include providing them with the knowledge and skills to advocate for their students and families, to "give voice to the unheard and power to the marginalized" (Strawn, 2009, p. 37). Preparing young teachers for challenging an entrenched educational system requires the academic freedom of the university as well as the knowledge and expertise of the university faculty. Kate spoke of an ineffective teacher who was "green." Perhaps our "green" teachers, in addition to training in effective methods, need a stronger background in understanding the legal and human rights of the students and families whom the serve.

Colleges of education need to acknowledge their role in training teachers to work within a framework of equitable education. Programs in general education should recognize the value that students with disabilities bring to the classroom. Providing additional training in working with students with disabilities as well as promoting accepting attitudes would go far in fostering a more inclusive environment.

## Parents' Voices

Kate, Carol, and Theresa were articulate and informed about their desires to see their sons placed and accepted in general education settings. Yet, David, Nick, and Thomas were relegated to segregated, "D" level classes. Apparently the schools' decision-making processes did not give weight to the mothers' knowledge of their sons' strengths. IDEA mandates that parents are given voice in decision-making, not just token attendance at IEP meetings. Fish (2008) suggested that "Educators should value parents as equal partners to facilitate a cooperative rather than an adversarial environment during IEP meetings" (p. 13). Given the comments from all three mothers, it is difficult to see that the parents were considered partners, much less equal partners in the IEP meetings. In fact, Carol pointed out the adversarial relationship that the school assumed would be the tenor of the IEP meetings. The young men attended different schools; yet, each parent had similar experiences of lack of influence in the placement of their sons. This may imply that the district, or even the state, does not afford parents the respect that they deserve. If such is the case, as well it may be, then the significance of parental input is preempted by widespread bureaucratic practices that accommodate the system and not the families. Carol explicitly stated that she believed the IEPs were "for the system." In addition, she commented that the initial reaction of the IEP team was that Nick's Down syndrome should dictate his placement – another clear violation of the federal statute. Theresa's plea for information indicates that the school system does not oversee the dissemination of information to parents. This was particularly noted in the lack of assistance in transition services. IDEA included specific requirements for secondary transition

Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually thereafter, the IEP must include:

- Appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment and, where appropriate, independent living skills;
- The transition services (including courses of study) needed to assist the child in reaching those goals (20 U.S.C. 1414 (d)(1)(A)(i)(VIII)(aa)).

The parents in this study were left, in many ways, to their own devices in finding the transition services for their sons. Carol stated that finding the courses of study at a state college was the result of a personal search and not forthcoming from the school or district.

#### Students' Voices

Nick and Thomas did not have any recollections of their IEP meetings, and David recalled only one which centered around his mental illness. David also commented that the team did not ask him about what they were including in his IEP. Article 7 of the UN Convention on the Rights of Persons with Disabilities asserts that children have the right to express their opinions and have their opinions considered in decision-making. [It is of interest to note that during the writing of this dissertation the Convention was approved by the Senate Foreign Relations Committee but was rejected by the Senate for ratification.] If students are not included in decisions regarding their educational plan – which includes placement – then their voices are not given due respect. David, Nick, and Thomas, were high school students who have knowledge of themselves, their needs and their preferences, but they were not given the opportunities to express their ideas in planning their programs. Nick, in particular, demonstrated

his ability to speak up for himself in the way he handled an unpleasant situation with an educational assistant and in convincing the school principal to allow him to leave campus with his friends. Yet, he was not afforded the chance to speak up for himself in what should have been an effective forum for him to influence decisions made about him and to learn the skills to participate in a group to plan his supports, skills that will serve him throughout his life. In my practice I have observed IEP meetings in which a phalanx of school personnel talked around and about a student as if he were not present. Infrequently, a support teacher might turn to the student and ask if he agreed with what had been decided for him. Many students with intellectual disability can be intimidated by the authority of the teachers and others who surround them and these students will accede to whatever is the majority opinion. Pressuring a timid "Yes" from a student does not constitute hearing what a student has to contribute.

David was thoughtful and articulate. Had he been allowed to influence his IEP meetings, perhaps he would have been included in a general education language arts class where he could hone his skills in reading and writing as well as enrich the social environment of his classmates. If Nick were given the opportunity to effect changes in his placement, he might have enlivened general education classes with his natural ebullience and warmhearted friendliness. He certainly would have had much to offer to class discussions. If he can be a global ambassador for Special Olympics, he certainly could have been an emissary for tolerance and acceptance in high school classes. Perhaps, if Thomas had been able to influence his placement, he may have been able to form relationships that were more long-lasting and substantive. He might have found the teacher who would say, "There's a good person right there," and open doors for him to greater acceptance into the general school community.

## Limitations of This Study

The most immediate limitations are the choice of a convenience sample and the small sample size. Both these factors limit generalization to a larger population. The nature of qualitative research, especially portraiture and IPA, necessitates keeping the sample size small. My research was an "attempt to capture something of the multiple realities and visions" (Lawson, Parker & Sikes, 2006, p. 65) of the participants. Additionally, all the participants live in the same city; the students were all enrolled in the same school district. Some of their experiences may be particular to the district and may not be applicable in other locations or school systems. The participants own their stories and the unique nature of their experiences limit generalization. Regardless of the attempt to be objective, predispositions influence the study. The narrative nature of the study may not disclose the participants' biases. Although my personal biases are revealed, there is still the possibility that they overreach into the creation of portraits and analysis of participants' responses. I attempted to limit this bias by personally reflecting on each portrait and by sharing my findings with a colleague and the members of my dissertation committee, noting their recommendations and adjusting interpretations that were not supported by the data. The relationship between interviewer and interviewee sometimes implies an imbalance of power, thus eliciting stories that are meant to please the researcher. To address this issue, the surroundings were casual and chosen by the participants and I maintained a conversational style, assuring the participants that it was their stories I wanted to hear and was not seeking opinions to validate my preconceived notions. As included in Table 2, I made strenuous efforts to assure transparency and trustworthiness.

# Implications for Future Study

The issues that arose in this study indicate that some schools and school systems do not comply with IDEA. Further research may find that this is a pattern in the educational system that needs to be addressed. The value of teachers in this study was "hit and miss," some bringing passion and skill to their teaching and others neglecting their obligations to their students. It would be useful to investigate the practices and dispositions of both special and general education teachers in regard to students with intellectual disability to determine if this inconsistency is pervasive and to consider remedies. Looking into teacher education programs might also reveal the aptitude and attitudes of young teachers who are being considered for the teaching profession and whether or not they are trained to value the role of families and students with disabilities in planning methods and curriculum.

An overview of the responses of the participants in this study indicates that they faced practices that can be construed as unjust. This study can be seen as a springboard into future investigations of the violations of social justice that may be exist in the bureaucracies of school systems.

# **Appendix**

Typical questions asked of the participants

#### Former students:

- What do you remember about your friends in high school?
- What was the best part of high school? Tell me more about it.
- What was the worst part of high school? Tell me more about it.
- What do you remember about your IEP meetings? Tell me about them.
- What kind of activities were you involved in?
- What do you remember about your teachers?
- Did you have a favorite teacher? Tell me about him/her.
- What would you say to your teachers now that you have graduated?

## Family members:

- What were the experiences with your son in high school?
- Was your son included in general education?
- Please tell me more about your son's classes.
- Please tell me about your son's teachers.
- Please tell me about your son's IEP meetings.
- What were your experiences with transition from high school to postsecondary?
- What advice would you give to parents who have sons or daughters with intellectual disability about attending high school?

NOTE: These questions are similar to those actually used in the interviews. The interviews included other questions that were derived from the words of the participants.

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