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WHOSE I.D.E.A. IS IT ANYWAY? A LOOK AT THE INVOLVEMENT OF HIGH SCHOOL STUDENTS WITH LEARNING DISABILITIES IN THE INDIVIDUALIZED EDUCATIONAL PLANNING TEAM PROCESS

presented by

Norma J. Schutzki

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WHOSE I.D.E.A. IS IT, ANYWAY? A LOOK AT THE INVOLVEMENT OF HIGH SCHOOL STUDENTS WITH LEARNING DISABILITIES IN THE INDIVIDUALIZED EDUCATIONAL PLANNING TEAM PROCESS

By

Norma J. Schutzki

A DISSERTATION

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2001

Professor Maenette Benham, Chair
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Professor Aaron Pallas
Professor Gary Sykes

ABSTRACT

WHOSE I.D.E.A. IS IT, ANYWAY? A LOOK AT THE INVOLVEMENT OF HIGH SCHOOL STUDENTS WITH LEARNING DISABILITIES IN THE INDIVIDUALIZED PLANNING TEAM PROCESS

By

Norma J. Schutzki

Purpose

The purpose of this study was to examine the perspectives of high school students with learning disabilities (LD) with regard to their involvement in the planning and implementation of their special education programs and services as mandated by the Individuals with Disabilities Education Act. Despite the growth of special education programming intended to meet the needs of LD students, students with learning disabilities have lower graduation rates, higher rates of unemployment, perform less well in post-secondary studies, and live less independently than non-disabled students.

Programming successfully for LD students is the subject of much tension in the field of special education. Within all the controversy, the voices of the student stakeholders themselves are seldom heard or acknowledged. Self-determination theories offer an explanation of the reduced motivation and "buy-in" by stakeholders whose individually expressed values and needs are not considered.

Sample and Method

The sample for this study was comprised of nine high school students who qualified for special education programs and services as learning disabled and

their parents. The students and parents were individually interviewed using an informally structured, open-ended interview protocol. Interviews were audiotaped and transcribed. A cross-case analysis was undertaken to uncover common themes from the coded data. Results were validated through the use of field notes documenting student participation at meetings to plan their individualized educational programs.

Findings

Responses of students and parents were analyzed within a framework provided by Deci's theory of self-determination and labeling theories espoused by Branthwaite (1985), Langer (1983), and Mehan et al. 1986). Results from the study indicate that, while students want more voice in the individualized educational planning team process, they lack the capacity to assert themselves. The students more often relied on the support and advocacy of entrusted others to represent their wants and needs

Recommendations

This study revealed the need for schools to take a more proactive approach with regard to providing students with both the skills and the opportunities for self-determination. The ecological model put forth by Mithaug (1996) provides a framework for a systemic approach to building the capacity of the students, their parents, teachers, and the various environmental contexts within which they participate to promote autonomous decision-making.

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DEDICATION

To my husband, Robert, and my children, Scott and Sarah,
whose love and support made this possible.

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There are many people whose support and assistance made the realization of this project possible. I would like to thank my advisor, Dr. Maenette Benham for her steady support and encouragement. She challenged me to stretch my thinking and gave me the confidence to continue with the study. Her dedication to her role as mentor and guide made this study possible. I am truly grateful for having had the opportunity to get to know and work with her.

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I owe much gratitude to the nine students and their parents who willingly participated in this study. Their perspectives provided me with many powerful insights into existing practices within special education, and I thank them.

I want to express my thanks to Lynne Waterman for her help in transcribing tape-recorded interviews and to Lee Sanborn for her efforts in helping to format and copy the dissertation. I also want to thank my friends who spent countless hours listening to my tales of woe and offering sage advice during frequent times of uncertainty.

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LIST OF ABBREVIATIONS

A.D.A. - Americans with Disabilities Act

E.H.C.A. - Education for All Handicapped Children Act (P.L. 94-142, enacted in 1975)

I.D.E.A. - Individuals with Disabilities Education Act

I.E.P. - Individualized Educational Plan

I.E.P.T.- Individualized Educational Planning Team

L.D.- Learning Disabled / Learning Disabilities

L.R.E. - Least Restrictive Environment

M.E.T. – Multidisciplinary Evaluation Team

PL 94-142 – Public Law 94-142, also known as the Education for All Handicapped Children Act

R.E.I. - Regular Education Initiative

CHAPTER 1

INTRODUCTION

Purpose of the Study

It has been quarter of a century since the landmark legislation, Public Law 94-142 (PL 94-142), Education for All Handicapped Children Act (ECHA), was enacted in 1975, affecting many practices in education. This law, reauthorized in 1990 as the Individuals with Disabilities Education Act (IDEA), was intended to address the civil rights of millions of handicapped children whose educational needs had heretofore been largely ignored. It ensures access to a free, appropriate public education (FAPE) for all students, regardless of any handicapping condition. Public school districts that fail to comply with the mandate to provide appropriate programs for disabled students stand to lose their federal funding.

The past twenty-five years have seen a tremendous growth in the number of students eligible for special education and a proliferation of programs and services intended to meet their needs, along with the spiraling costs to districts of maintaining these programs. Students with learning disabilities (LD) comprise nearly half of all identified special education students; thus a large proportion of district and state funding is directed toward supporting programming that addresses their educational difficulties. There is ongoing debate, both within the education field and by outside observers, as to whether or not special education is doing its job. Educators, university researchers, politicians, and journalists continue to pose the question as to just how accomplished special education has

been with regard to producing students who go on to be successful in their post-secondary endeavors. The voices that are rarely heard are those of the special education students themselves.

The purpose of this study was to determine, from the perspective of secondary student stakeholders who have been identified as having learning disabilities, the factors that influence how they mediate the system to access the special education services prescribed, by their individualized educational planning (IEP) team, to support their academic success. The purpose was also to discover how important these students believe it is to have voice in the development and implementation of their plans. This study was also intended to discover the extent to which such students believe that they have been empowered, as is the intent of the law, with regard to their input in the decision-making process, what this empowerment "looks like," and in what ways students would alter current programming to better meet their needs. The study addressed the question, "What factors influence the ways in which secondary LD students mediate access to special education programs and services through their participation in the individualized education planning team process?" It is hoped that the results of this research will serve to influence educators and policy-makers to pay increased attention to issues of student empowerment and self-determination.

Overview of the Study

Chapter I, the Introduction, describes the purpose of the study, provides a statement and an overview of the problem being investigated and the factors that

shape the involvement of secondary LD students in the development and implementation of their IEP, and addresses the need for and significance of this study. The analytical lenses of self-determination theory and theories regarding the effects of labeling are also described. This chapter also includes a discussion of the delimitations, assumptions, and research questions addressed by the study.

Chapter 2 contains a review of the related literature, focusing primarily on the history and underlying principles of IDEA, current implementation practices and resulting tensions within the field of special education. Theories regarding student empowerment, self-determination, and labeling, which comprise the lenses through which the data will be analyzed, will also be reviewed. Studies reporting special education student perspectives and student empowerment will be given particular attention.

The research design, methodology, research site and sample selection for this study are described in Chapter 3. Other, related, studies using similar research methods are described there as well. The presentation and analysis of the research findings are contained in Chapter 4. Chapter 5 provides a discussion of the significant findings and relates the study to current theory and existing research. Implications of the study with regard to current practice and recommendations for further research will also be discussed.

Statement of the Problem

Legislation to protect the rights of the disabled is a fairly recent phenomenon. From 1700 until the 1920's, disabled individuals were

"warehoused" or "hidden away in the attic" (Funk, 1987). Beginning with 1900, the passage of compulsory school attendance laws and child labor laws indicated a growing concern on the part of the public with regard to protecting the rights of minors (Gartner and Lipsky, 1989). Between 1920 and 1960, policies and programs to address the needs of disabled people began to be developed. The "separate and unequal" decision in Brown versus the Board of Education in 1954 pioneered the beginning of desegregation and other civil rights legislation. The birth of the civil rights movement during 1960 through 1975 was a "watershed era in U.S. civil rights reform," and sought equality of opportunity for those who were disenfranchised and disadvantaged by virtue of their gender, poverty, racial, or ethnic background (Funk, 1987).

Special education, as we know it today, can be traced to the passage of the Rehabilitation Act of 1973, "established to develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living" (Funk, 1987, p. 16). In 1975, the landmark legislation, Education for All Handicapped Children Act (EHCA), also known as PL 94-142, heralded the beginning of an era aimed at ending separate and unequal opportunities for the handicapped and at ensuring that handicapped children would be educated with their non-handicapped peers. The proliferation of special education programs and services that followed the passage of this law has led to much debate within the field and has caused many to question whether or not we have been successful in carrying out the intent of the law:

> Public Law No. 94-142 was a lighthouse for disabled children and youth in our schools. It asked much of state and local officials, it promised much to parents and children, and it added much to our understanding and sensitivity about disability. Its careful analysis provides a picture of the status of disabled children and youth in our nation's schools. To what extent has the underlying purpose of the Education for All Handicapped Children Act – the integration of disabled children in our classrooms and the improvement in quality of their education – been accomplished? To what extent have the detailed requirements of this law structured the reform of education for children with disabilities and their treatment by educators and administrators? (Walker, 1987, p. 98)

Efforts to comply with the law have resulted in what has become a dual and parallel system of regular education and special education, with separate and distinct laws, funding formulas, instruction, administration, professional jargon and affiliation, and teacher preparation programs. In the opinion of many researchers, "Such a dual system perpetuates inefficiency and unnecessary competition in the delivery of educational services to all students. This dichotomy in the structure of school systems poses a particular challenge to improving the education of children characterized as mildly handicapped" (Hagerty and Abramson, 1990).

That school districts have attempted to rise to the letter of the law is evidenced by the profusion of students who have been identified as handicapped and eligible for special education programs and services. Numbers of identified students have skyrocketed since the inception of the Education for All Handicapped Children Act in 1975, increasing at a higher rate than the general school enrollment. According to the Twentieth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (1998), students with learning disabilities comprise the largest category, making up 51.1 percent

of all eligible students in 1996-1997. Of all students ages 12-17 eligible to receive special education in that year, 62.3 percent were diagnosed with a learning disability. That number represented a 37.8 percent increase over the past ten years, making learning disabilities the fastest growing category. The Report states, "Specific learning disabilities is the largest single category for each of the three age groups, accounting for 41.2 percent of students ages 6-11, 62.3 percent of students ages 12-17, and 51.7 percent of students ages 18-21."

This increase in eligible students has led to corresponding cost expansion. Data gathered by the federal government suggest that the per pupil special education expenditures have grown at about twice the rate of general education expenditures – an average of 4.1 percent versus 2.1 percent annually. The funds appropriated under IDEA, Part B, Section 611 Grants to States Program, have increased from $251,770,000 in 1977 to $3,109,395,000 in 1997, with the per-child allocation increasing from $71 to $535 during the same period (Twentieth Annual Report to Congress, 1998). Such a huge drain on districts' general funds diminish the feasibility of continuing to maintain a parallel educational structure to meet the unique needs of special education students.

States have been unable to keep up with the burgeoning costs of special education programming without the financial support that was pledged by, but has not been forthcoming from, the federal government. Indeed, in Michigan as in many other states, the funding situation has become so severe as to incite many school districts to file suit against the state to compensate them for the costs of underfunded mandates. The recent Durant (1996) case symbolizes the

conviction of many, that federal and state governments must be held accountable to fund the programs they mandate. The need to reevaluate the exorbitantly expensive yet continually underfunded extant special education system becomes even more critical when we examine graduation and post-secondary success rates of the learning disabled student population.

In today's society, characterized by a decrease in high paying manufacturing jobs and an increase in service and technology industries that require a higher degree of entry level skills, it is more important than ever for students to complete their high school education. Despite growing expenditures, current special education programs are falling short of the mark in terms of turning out high school graduates with the requisite skills for success. In fact, in the 1996-1997 school year, only 32.9 percent of students 17 years and older with specific learning disabilities graduated with a diploma or Certificate of Completion (Twentieth Annual Report to Congress, 1998). While graduation rates for other groups are gradually improving, those for students with learning disabilities remain rather dismal. As stated in the Twentieth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (1998),

> The national education goals state that by the year 2000, the high school graduation rate will increase to at least 90 percent. The high school completion rate for all students in the United States rose considerably in the early 1980's but has been relatively stable since then. In 1992, the rate was 87 percent for youth ages 19 and 20. Notable are increases in high school completion among African Americans; their graduation rates are now equal to those of Whites. However, much lower graduation rates are reported for Hispanic students and students with disabilities.

Students with learning disabilities also fare poorly during their post-secondary years.The Twentieth Annual Report describes their situation as follows:

> Three to five years after leaving high school, fewer than 25 percent of youth with disabilities had been enrolled in post-secondary education, many were engaged in low-wage jobs with few opportunities for advancement, and more than half continued to live in their family homes.

It is particularly significant to note that one of the primary purposes of IDEA is to ensure that all students with disabilities have an education that prepares them for employment and independent living [20 U.S.C.1400 (d) (1) (A)]. Yet, despite extensive and costly programming, only 57 percent of all youth with learning disabilities are employed as compared to 69 percent of the general population. Researchers from the University of Kansas Institute of Learning Disabilities (KU-IRLD) agree that educators need to examine the ways in which schools prepare students with learning disabilities for post-secondary life (Schumaker and Deshler, 1990). Compared to non-LD students, results from three studies conducted through the KU-IRLD show:

- post-secondary school demands emphasize listening, note-taking, working independently, completing assignments, writing themes and essays, studying for and taking tests.
- LD young adults have difficulty with social and independent living skills.
- 70 percent of LD students (as opposed to 45 percent of non-LD students) still live with parents or relatives.

- LD students have significantly less participation in reading, hobbies, or sports activities.
- LD students have significantly more contacts with law enforcement authorities.
- 46.4 percent of LD students have difficulty knowing how to study.

That our schools do a less than satisfactory job of programming for students with learning disabilities should come as no surprise to those who ascribe to a view held by a growing number of authors (Hahn, 1985; Iano, 1985; Heshusius, 1989; Gelzheizer, 1990; and Sleeter, 1990) who believe that we have approached the task of special education from the wrong perspective; that all of our existing models (medical, psychological process, behavioristic, cognitive learning strategies) share a mechanistic/reductionist heritage in which the child has to be reduced in order to be understood. Each of the above models erroneously "(a) assumes that the problem of not learning is within the student; (b) segments learning into pieces (be it pieces of auditory/visual processes, pieces of behavior, or pieces of cognition); (c) is deficit driven, linking directly to instruction the perceived problems in the pieces of processes, behaviors, or cognition; (d) conceives of teaching as unidirectional; that is, the teacher gives to the student the preset tasks in a preordained sequence; (e) assumes that there are correct and incorrect strategies, facts, behaviors, and processes, that is strategies, behaviors, and so forth, that directly, linearly, and indisputably flow from theoretical assumptions of the particular theory; and (f) reduces life goals almost exclusively to school goals" (Heshusius, 1989, p. 406). It is Heshusius's

contention that "A powerful solidification of mechanistic thought is seen in the mandates of Public Law 94-142" (p. 406).

Current assessment procedures mirror this philosophy, testing only a student's abilities along a narrowly defined continuum of skills. Indeed, the LD category is currently composed of only seven different types of disabilities, including deficiencies in: (1) listening comprehension, (2) oral expression, (3) basic reading (decoding, sight word recognition), (4) reading comprehension, (5) written expression, (6) arithmetic calculation skills, and (7) mathematics reasoning (Lyon and Alexander, 1997). Such assessment largely ignores measuring the broad array of skills necessary to succeed in the secondary curriculum, notably: note-taking ability, critical listening skills, independent study habits, and test-taking ability (Schumaker and Deshler, 1990), and results in intervention programs that are too narrow in scope.

Instead of our current system, Heshusius (1989) advocates a shift in paradigm so that, rather than grounding our programming decisions on a medical model which views a disability as a deficiency within an individual, we would interpret disability as a mismatch between a person and their environment. Because "The probability of designing interventions that allow handicapped adolescents to cope with the demands of secondary schools is increased only to the extent that assessment practices measure both student and nonstudent variables" (Schumaker and Deshler, 1990, p. 134), assessments under alternative models would include factors such as teacher behaviors, curriculum

expectations, response requirements, and social expectations (Schumaker and Deshler, 1990).

Special education programs based upon these more comprehensive assessment procedures would be developed by teachers who would rely on their judgement, creativity, and imagination when interpreting a student's learning difficulties, and shape educational programming accordingly. Student involvement in their learning is also critical:

> Research efforts suggest that the education of LD adolescents is facilitated if they can be made aware of (a) their own strengths and weaknesses as learners, (b) basic task-specific strategies for gaining and expressing information, (c) procedures for analyzing setting and task requirements, and (d) procedures for designing strategies to facilitate their ability to cope with setting and task requirements. Such self-awareness is seen as essential to the ultimate development of self-regulation skills in LD students, including the ability to plan, monitor, orchestrate and check their own learning and performance" (Schumaker and Deshler, 1990, p. 153).

Students who are not involved with their learning may not exert any effort toward their achievement. Influenced by such researchers and philosophers as Freire and Vygotsky, Heshusius maintains that the very art of teaching centers on facilitating student empowerment. This study sought the perspective of secondary students with learning disabilities regarding their experiences in special education. It looked at the factors that influenced the ways in which the students mediated access to the programs and services, and were involved in the development and implementation of their individualized education programs.

The Need for and Significance of the Study

Studies evaluating the comparative effectiveness of various modes of special education programming are profuse. The literature documents the

arguments of educators supporting traditional and non-traditional forms of special education service provision. Most of this research, however, focused on input from parents, teachers, and educators, with little attention given to the perspective of the student. When, despite expansive and expensive programs intended to provide them with academic assistance, students don't succeed, we tend to blame the "victim," locating the failure within the students themselves. If we were to attend more to environmental factors and recognize the mismatch that may be occurring between the school environment and the student's individual learning style and instructional needs, we might realize that the programs we have developed do not actually serve the students as we intended.

That students feel strongly about having voice in educational decisions that directly affect them became evident to me during my tenure, first, as a special education teacher and, second, as a district level administrator. During the eleven years that I taught elementary level students with emotional impairments and learning disabilities, I was able to observe, firsthand, how the ability to have choice influenced the students' motivation and engagement in the learning process. This point was made even stronger when, for the purpose of fulfilling a course requirement for graduate school, I interviewed my students to see how they felt about receiving special education services in a pull-out program as opposed to receiving support services within an inclusive setting.

The depth of emotional response elicited by my questions surprised me. Although the study was narrow in scope (I interviewed only the fourteen students on my caseload), the range of responses was greatly varied. The students who

responded that they did not want to be in a special education class at all were, at times during the interview, moved to tears. It was at this point that I realized the importance of involving students in decisions regarding special education program and placement options.

Other examples of students' need to be empowered have similarly influenced my thinking. For a research practicum, I interviewed fourth grade students with learning disabilities to learn their feelings about participating in class with their special education and regular education peers. I became acutely aware that, even at this young age, students had a keen sense of their and their peers' academic and social standing. These fourth graders were able to articulate their perceptions regarding their abilities, strengths, and weaknesses, both academic and social, in comparison with those of their classmates. They had very concrete ideas regarding changes that could be made to improve the academic and social situations they faced in school.

Recently, in my role as a district-level administrator, I participated in a town meeting held by my school district as a way of encouraging communication between the district and the community at large. The subject of this meeting was school safety and, during the first part of the evening, members of the audience were invited to share what they believed should become the priority of the school board in helping to establish a safe school environment. Approximately three hundred residents and school personnel were in attendance that night, including about fifty high school students. These students were unabashed in sharing their concern, anger, and frustration about certain steps the district had undertaken to

insure their safety. They were infuriated by the discovery that the district had recently purchased and installed surveillance cameras in their school. They expressed their opinion that locked doors and security systems served to undermine the climate of friendliness and warmth that they had come to expect. Time and again that evening, students came to the microphone and demanded to be included in the conversation and decision-making process concerning any precautions that would be taken to secure their environment.

While having voice in the educational decisions that affect them appears to be very important to students, little research to date has student input as its basis. Numerous studies exist that include the opinions of parents, teachers, school administrators, and members of university education departments, but few have surveyed the students, themselves, to ascertain their perspectives. The Individuals with Disabilities Education Act was reauthorized in 1997 to require student input, no later than age fourteen, in the development of the IEP. Ironically, the Twentieth Annual Report to Congress on the Implementation of IDEA lists as indicators of program success input from parents and teachers, but fails to include student feedback in the formula.

To be sure, several researchers (Deci and Chandler, 1986; Murphy, 1992; Schumaker and Deshler, 1990; Stainback and Stainback, 1992; and Taylor et al, 1989) comment upon the paucity of research in this area, and recommend that future studies include the student perspective. In his research involving adults with learning disabilities, Murphy (1992) advocates for continued investigation into the perspective provided by students with learning disabilities:

> Very little investigative attention has been paid to studying learning disabilities from the vantage point of those who have been so labeled. Numerous writers, however, have attested that an inside perspective will provide much needed depth to our understanding of the learning disabilities experience, and of the societal treatments and policies that have been designated as remediation ....Of particular importance has been the failure of researchers to really explore how persons called learning disabled have operationally defined school, social and employment experiences, self-concept, and life satisfactions; and how they have confronted or denied these experiences and issues in everyday situations (Murphy, 1992, p. 15-16).

Taylor, Adelman, Nelson, Smith and Phares (1989) conducted research in the area of student voice and empowerment and stated, "In general, the findings support other studies showing that youngsters have strong perceptions and attitudes about participating in processes affecting their lives and that the impact on their actions is profound" (p. 439). It was toward this end that this study was directed: The focus of this research was to discover and describe the factors that influence the ways in which secondary students with learning disabilities mediate access to special education programs and services through participation in their IEP team meeting. The extent to which they give voice to their wants and needs during the development and implementation of their individualized education plans was also examined.

Analytical Lenses

This study adds to the field of special education the unique perspective of special education students with regard to their empowerment and ability to be meaningfully engaged in their learning. Through interviews and observation, this study provides what other, quantitative research does not, that is: a student perspective regarding the ways in which they participate, or not, in the

development and implementation of their individualized education plan. Previous research efforts "do not address the question of how students actually construct the meaning of their school situation, and therefore they can't tell us anything about what really motivates students" (Heshusius, 1989, p. 411). Self-determination (Deci) and labeling theory (Becker) served as the analytical lenses through which the data were evaluated.

In conjunction with the sentiments expressed by Taylor et al. (1989), this research supports the premise that students will more deeply invest themselves into processes they have had a role developing, and agrees with the importance of examining issues regarding individual control. "Numerous theorists have stressed the importance of independently considering an individual's (a) perceptions about the process (e.g., actions, events) necessary to accomplish a specific outcome, (b) expectations about the degree to which one can control the processes, and (c) expectations about accomplishing the outcome.... Minors, including those in special education programs, can voice clear perceptions about their sense of control in school and clinical settings" (Taylor et al., 1989, p. 439). Their findings also showed that older students, especially, rated the issue of control more highly than did younger students.

This study of secondary students with learning disabilities generates additional knowledge and insights that may prove quite valuable to educators seeking to develop effective, supportive programs for students. In the present climate of school restructuring efforts, the findings from this research may also inform policy makers charged with creating educational policy.

Delimitations of the Study

This study does not attempt to:

1) Make an argument for or against a particular programming philosophy such as inclusion or maintaining a full continuum of services. This subject has already been examined and discussed at length in a plethora of publications, several of which will be reviewed here for the purpose of providing an understanding of current tensions in the field of special education.
2) Examine the implementation of any part of the IDEA other than part B (programs and services for students from 6-21). The scope of a study that includes services to infants, toddlers, preschoolers and post-secondary students far exceeds the intent here.
3) Examine the provision, or non-provision, of programs or services to students with learning disabilities who are enrolled in private or charter schools.
4) Examine the effects of gender, race, ethnicity or social class on the identification of students with learning disabilities.
5) Evaluate the existing prereferral and referral processes for students suspected of having a learning disability.
6) Critique the present system of evaluation and identification of students for special education eligibility, other than to discuss how these processes are perceived by students.
7) Address the variation in special education funding formulas utilized by different states.

8) Address the existing teacher preparation programs nor the current situation involving a critical shortage of teachers certified to teach special education.
9) Address similar issues with regard to other special education populations (such as students identified with emotional impairment, mental impairment, physical or other health impairments, multiple impairments, hearing or visual impairments, etc.). The population of students with learning disabilities was selected as the focus of this study due to the fact that they comprise nearly half of all students identified for special education, and a major share of special education allocated funding is expended on their behalf, with less than satisfactory results. The high school level was selected due to the IDEA mandate that students age 14 and above are to be invited to participate in their IEP team meetings.

Assumptions

This study is based on the following assumptions:

1) Public schools in all states are implementing, in a variety of ways, the programs and services that are mandated under IDEA, including the mandate for student participation beginning no later than age 14.
2) All public school districts have some form of student evaluation and special education eligibility process.
3) Procedures for funding IDEA mandated programs and services vary from state to state.

4) There are diverse forms of academic support made available to students found eligible for special education under criteria for learning disabilities, resulting in a diversity of student experiences.

Research Questions

The mandates of the Individuals with Disabilities Education Act (IDEA) serve as the foundation upon which district special education programs are developed and implemented. The IDEA is based upon several major principles which drive and guide programming decisions. Historically, school administration, teachers, parents, disability advocates, and lobbying groups have been the major influence in the development of programs to meet the specific needs of students with disabilities. Students have had little, if any, voice in such matters.

This study attempted to answer the question, "What factors influence the ways in which secondary students with learning disabilities mediate access to special education programs and services through 'voice' in the development and implementation of their individualized education plans?" Research questions were formulated within the framework of the major principles of the IDEA. Toward this end, students were asked to reflect upon and discuss their understanding of and participation in their school's efforts to uphold the basic principles of IDEA, namely:

1) the provision of a free and appropriate public education (FAPE);
2) the provision of an appropriate evaluation, initially and every three years after an initial determination of eligibility has been made;
3) the provision of an individually designed education plan (IEP);

4) the provision of an education that, to the greatest extent possible, takes place in the least restrictive environment (LRE), that is, with non-handicapped peers in the general education environment;
5) the invitation to participate in the development and implementation of such a plan, especially at age 14 and beyond.

Students responded to open-ended interview questions by recounting their personal stories with regard to the processes involved in their special education evaluation, diagnosis and labeling, and program planning. Questions focused on the following themes:

1) Students' understanding and acceptance of their disability

- What do high school students with learning disabilities understand about the etiology of their disability? When did they first become aware that they had a disability? How was this explained to them? (Evaluation and diagnosis)
- What do high school students with learning disabilities believe to be the impact of their disability on their academic and social school careers? (Diagnosis/labeling)
- How do high school students with learning disabilities believe that they are perceived by their peers? (Labeling)

2) Students' perceptions of the ways in which their special education programming has been individualized to provide appropriate academic and/or social supports

- How do students feel about the appropriateness of their special education programming with regard to meeting their needs? [Individualized education plan (IEP)]
- What do students see as the barriers to a successful high school career, and do they believe that their special education programs and services are structured to assist them in overcoming these barriers? Do they predict that they will graduate from high school? Continue on to some post-secondary form of education or training? [Free, appropriate public education (FAPE); Individual educational plan (IEP)]
- What do students perceive about the effect of their special education program on their ability to interact with non-disabled peers in the regular education environment? [Least restrictive environment (LRE)]

3) Participation by students in their educational programming decisions beginning no later than age 14

- In what ways do high school students with learning disabilities believe, or not, that their voices have been counted with regard to developing and implementing special education programs and services?
- What steps has the school taken, or not, to encourage and facilitate high school students with learning disabilities to participate in their educational decision-making?
- What factors serve as barriers to involvement of high school students with learning disabilities in their short-term and long-term educational programming decisions?

- What supports, if any, do high school students with learning disabilities view as necessary for their involvement in the development and implementation of their individualized education program?

Chapter 2

REVIEW OF RELATED LITERATURE

Knowledge of the history and original intent of the IDEA and its actualization into daily practice in school districts is critical to understanding the potential role of the student in the development and implementation of his or her individualized education plan (IEP). The law, from its initial implementation through prevailing practices, is described. Current tensions in the field are examined as they relate to the ways in which various districts have chosen to implement special education programs and services. A discussion of the recent reauthorization of the law (1997), with its new emphasis on student involvement, serves as the foundation on which an argument for the need to increase student empowerment is constructed. Current theories, which emphasize the importance of personal involvement and opportunities for self-determination serve as analytical lenses through which to interpret student responses.

History and Intent of the Individuals with Disabilities Education Act

The Education for all Handicapped Children Act (EHCA) of 1975, otherwise known as PL 94-142, was born in an era characterized by an overarching emphasis on civil rights as evidenced in 1954 with the "separate and unequal" decision in Brown versus the Board of Education. This law was also preceded by the Rehabilitation Act of 1973, which set a historical precedent by seeking to guarantee vocational rehabilitation and independent living for adults with disabilities. It can be said that the "separate and unequal" decision reached in the case of PARC vs. Mills, which questioned the legality of the previously

accepted practice of denying public education to a class of students based on their handicap, heralded the birth of the EHCA. A new generation of parents now served as advocates who sought to protect the rights of their disabled youngsters and prevent their exclusion from and discrimination in the public school setting. Walker (1987, p. 97) describes the political climate surrounding the emergence of this law:

> Following three years of hearings, a decade of court cases, and prior congressional and state legislative actions, this legislation codified a baseline of rights, procedures, and guidelines for intergovernmental relationships that have defined public policy for children and youth with disabilities in educational services and, to some extent, in other social services as well. While it is not wholly unambiguous, Public Law Number 94-142 is the clearest expression by government of the rights and expectations of persons with disabilities in law.

The EHCA, which now guaranteed a public education to a previously underserved population of 4,000,000 children with disabilities, was reauthorized by Congress in 1990 and renamed the Individuals with Disabilities Education Act, or IDEA. This law has as its framework six basic principles to help ensure better educational results for students with disabilities. This study directly involves five of these principles, which serve as the basis for all special education programs and services:

1) The right to a free, appropriate, public education (FAPE);
2) An appropriate evaluation to determine initial and ongoing eligibility for special education programs and services;
3) An individualized education plan (IEP) formulated for each eligible student and intended to address specific deficit areas;

4) Education that is provided in the least restrictive environment (LRE) that is, whenever possible, with non-handicapped, age-appropriate peers; and

5) Parent and student participation in decision making.

The ways in which these principles have been interpreted and reflected in actual practice by school districts have served to create many tensions now existing within the field. For the purpose of this study, discussion will focus on the literature describing the debate surrounding the various practices intended to uphold each of these principles, and on research affirming the importance of empowering the student to be an active participant in the decision-making process.

Free Appropriate Public Education (FAPE)

Before the passage of PL 94-142, nearly half of the 8,000,000 children identified with special needs were not provided a public education that addressed their disability. The IDEA guarantees students with disabilities a free appropriate public education. This has been defined by the IDEA [Section 602(8)] to mean special education and related services that:

a) have been provided at public expense, under public supervision and direction, and without charge;

b) meet the standards of the State educational agency;

c) include an appropriate preschool, elementary, or secondary school education in the State involved; and

d) are provided in conformity with the individualized education program required under section 614(d) of this title.

What constitutes a "free appropriate public education" has come to mean different things to different people. Debate continues to center around the responsibility for ensuring that a student's IEP, with its goals and objectives, is implemented in the least restrictive environment (LRE). Current tensions as they exist with regard to this issue will be discussed in the section discussing least restrictive environment.

Appropriate Evaluation

The IDEA requires that before a student can receive special education and related services for the first time, he or she must receive a "full and individual initial evaluation." According to the Twentieth Annual Report to Congress (1998), the law also requires:

- parental consent for the initial evaluation;
- a nondiscriminatory evaluation;
- evaluation by a team in all areas of suspected disability;
- not using any single procedure to determine that a child is a child with a disability or to determine the child's educational program;
- testing in the native language or mode of communication of the child, unless it is clearly not feasible to do so; and
- that local educational agencies (LEAs) conduct reevaluations for each child with a disability if "conditions warrant a reevaluation or if the

child's parents or teacher requests a reevaluation, but at least once every 3 years...," [614(a)(2)(A)]

The special education evaluation and labeling process continues to raise the hackles of many researchers and practitioners in the field. Authors such as Adelman (1992), Gartner and Lipsky (1987), Gelzheiser (1990), Hahn (1985), Heshusius (1989), Lipsky (1989, 1992, 1997), McDermott (1993), Mehan, Hertweck, and Meihls (1986), Sigmon (1990), and Walker (1987), among numerous others, decry the practice of classification and labeling and accuse it of ambiguity and capriciousness. The category of learning disabilities is a relative newcomer to the list of special education eligibility areas. Murphy (1992, p. 7) describes the evolution of this label:

> ...the term *learning disabilities* was coined by Samuel Kirk, a university professor of special education, during a 1963 speech at the Fund for the Perceptually Handicapped Conference held in Chicago. The conference was reportedly called by parents who, during the 1950's and early 1960's, were attempting to secure services for their low-achieving but otherwise normal children...it was this perceived neglect of children who appeared to be normal but who had specific kinds of learning problems for which there were no services, that stimulated parent groups to take political action.

"Learning disabilities" became officially recognized and institutionalized in 1963 with the creation of the Association for Children with Learning Disabilities, the result of intense lobbying efforts by parents (Sigmon, 1990). In 1980, the term received full medical approval with its inclusion in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, 3rd edition (DSMIII), and in the World Health Organization's publication, International Classification of Diseases (Murphy, 1992, p. 5). The definition itself has

undergone many changes and remains inconsistent from state to state and, in many cases, between different school districts.

The definition that has been adopted by most state departments of education and used as a guide toward the identification of students who qualify as learning disabled is that put out by the US Office of Education (USOE). This definition describes a learning disability as a

> disorder of one or more of the basic psychological processes involved in understanding or using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or of environmental, cultural or economic disadvantage (5B-4)(Murphy, 1992, p. 4).

Following this definition, an alternative version, which attempted to minimize some vague, confusing phrases, was proposed in 1981 by the National Joint Committee for Learning Disabilities (NJCLD), and defined the term as follows:

> Learning disability is a generic term that refers to a heterogenous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing and reasoning, or mathematical abilities. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunctions, and may occur across the life span. Problems in self-regulatory behaviors, social perception, and social interactions may exist with learning disabilities but do not by themselves constitute a learning disability. Although learning disabilities may occur concomitantly with other handicapping conditions (for example, sensory impairment, mental retardation, serious emotional disturbance) or with extrinsic influences (such as cultural differences, insufficient or inappropriate instruction), they are not the result of these conditions or influences (NJCLD, 1988, p. 1) (Murphy, 1992, Pp. 4-5).

What these definitions have in common, and what many authors contend is the problem with such definitions, is that they posit the disability as a disorder that lies *within* the individual rather than viewing it as a mismatch *between* the person and his or her environment. Mehan, Hertweck, and Meihls (1986) assert that the practice of viewing learning disabilities as a medical condition situated within the individual gives credence to and serves society's need to evaluate and sort students to serve basic societal functions:

> The medical metaphor has been extended from the physical to the mental domain within education. As a consequence, intelligence, aptitude, or mental ability have become medicalized and subject to treatment. It is this medical metaphor that leads to the view that students have a "problem." This problem is a disability, perceived as residing within students, as their private and personal possession (p. 159).

These authors describe school as a "contest-mobility system" which functions to match talented students to higher level positions in society. Placing the disability within the child allows the school to ignore the truer issues regarding the need to examine their own "institutional arrangements."

McDermott (1993) describes the term LD as a political label, serving a rhetorical purpose as a way to talk about and analyze some children. He goes so far as to say that children do not acquire learning disabilities, they are acquired *by* learning disabilities. By this he agrees with the analysis of Mehan et al., that society has a need for some of its citizens to fail. McDermott proposes a "Field of Dreams" concept, "if you build it, they will come":

> LD exists as a category in our culture, and it will acquire a certain proportion of our children as long as it is given life in the organization of tasks, skills, and evaluation in our schools. In the daily construction of settings called educative in American culture, moments are put aside for

> the discovery, description, and remediation of certain children who display particular traits (p. 271).

The practice of evaluating and labeling is critical to schools whose special education programs rely on a medical model of academic diagnosis and prescriptive remediation. Adelman (1992) states that the research is equivocal about whether the good outweighs the bad regarding the practice of labeling for services, and calls for improving but not totally eliminating the current classification system. He recommends revising classifications for eligibility from their current, narrow focus on specific skill deficits to broader categories typifying mild, moderate, or severe levels of disability. He defines Type I as "disabilities" based on environmental deficiencies, while Type II and III represent more moderate and severe disabilities involving personal factors. Such an approach would serve to minimize the view of individual pathology and place the focus on addressing and restructuring the environmental context.

Adelman's sentiments are echoed by many others (Gelzheiser, 1990; Hahn, 1985; McDermott, 1993; Mehan, et al.,1986; Sigmon, 1990; and Walker, 1987) who advocate replacing the medical model with a socio-political model of disability which acknowledges the disabled as a minority group, and recognizes that their classification has often served political purposes and has been subject to social manipulation. Rather than construct programs that serve to remediate the deficiency *within* the individual, these authors call for restructuring the classroom and school environment to support the learning needs of *all* students, claiming that "special education policy and education policy are not separable" (Gelzheiser, 1990, p. 50).

The prevailing beliefs of these authors is that faulty instruction, inherent in existing school practices, is responsible for "victimizing" most mildly impaired students. Hahn (1985, p. 93) regards disability as the "consequence of a disabling environment," while Mehan, et al. (1986, Pp. 160-161) iterate that "disability, educationally speaking, is constituted by educational practices enacted as a routine part of organizational life ...If children are handicapped only in school, then it is possible to say that the school itself creates or generates handicaps." Sigmon (1990, p. 23) believes that learning disabilities are an "artifact" of past school reforms that have elevated standards for literacy and created a bigger gap between successful students and those with special learning needs.

While evaluating, diagnosing, and labeling students with learning disabilities may serve some purpose for the educational establishment and for the students, we must ask ourselves, "At what price to the student?" What are the consequences to the student of having an LD label, and programs and services that are tailored to meet specific skill deficits? How much damage are we doing to students subsequent to the evaluation and labeling process?

According to Branthwaite (1985), self-concept is influenced by three interacting variables: what we want to be; the way we present ourselves to others; and what society and other people tell us we *are.* Much of our identity is dependent upon the labels given to us by our parents and friends. Mehan et al. (1986, p. 107) corroborate Branthwaite's views, asserting that the label itself becomes a social "fact" about the child, which then acts as a metaphor to

describe the child. Mehan et al. (1986, p. 107) reflect on the power of the label in defining the child when they state, "...referred children are restricted and limited by the boundaries established by mythic discourse."

The power of the label is strongly corroborated by a series of studies conducted by Langer (1983). In her study with elderly residents in a nursing home, Langer found that the label of "nursing home patient" carried with it the subtle cues of incompetence, dependency, and membership in a "needier" class of individuals – the aged and infirm. Nursing home residents, inferring their own incompetence from the application of such labels, often just "gave up," becoming passive, dependent, and suffering symptoms of reactive depression.

In additional studies using samples drawn randomly from people waiting in airports, Langer found that the mere suggestion of a lower status, through a label, was enough to result in a decline in performance on a structured task. Subjects were randomly assigned the labeled of "boss" or "assistant" and asked to solve some puzzles. Those labeled "boss," the higher status label, consistently outperformed those with the label of "assistant," the label reflecting a lower, more dependent status. The power of labeling most certainly has implications with regard to studying the self-concept and motivation of students with learning disabilities.

How do students come to understand the educational evaluation and labeling process? What do they comprehend about the etiology of their academic struggles? How do they interpret the perceptions of others regarding their label? Are they able to acknowledge the fact of their disability and, if so, what do they

make of it with regard to their success in school and afterwards? These questions have been left largely unanswered to the extent that existing research has inadequately addressed the students' perspective.

Individualized Education Program (IEP)

The individualized education program, or IEP, serves as the backbone of the IDEA – the basis by which to ensure that the school addresses each specific deficit area of the eligible student. Section 614(d)(1)(A) of the IDEA defines the IEP and spells out its specific requirements:

> The term 'individualized education program' or 'IEP' means a written statement for each child with a disability that is developed, reviewed, and revised in accordance with this section...

According to the IDEA Amendments of 1997, the IEP must include a:

- Statement of the Child's Present Levels of Educational Performance – how a child with a disability is currently performing at school, emphasizing the child's strengths and weaknesses and areas that need to be addressed. This information is to be drawn from recent evaluations, observations, and inputs from parents and school personnel. The Amendments place a new emphasis on "how the child's disability affects the child's involvement and progress in the general curriculum" [614(d)(1)(A)(ii)(I)].
- Statement of Measurable Annual Goals, Including Benchmarks or Short-Term Objectives. This section focuses on the IEP team's recommended educational goals that are appropriate for the student. The goals must be annual and measurable and include benchmarks or short-term objectives, and relate to "meeting the child's needs that result from the child's disability to enable the child to be involved in and progress in the general curriculum; and meeting each of the child's other educational needs that result from the child's disabiltity [614(d)(1)(A)(ii)(I) and (II)].

The IDEA also calls for the provision of "Supplementary Aids and Services," meaning aids, services and other supports provided in regular education classes or related settings to enable children with disabilities to be

educated with nondisabled children to the maximum extent possible. Authors such as Walker (1987), who advocate against the use of labels, contend that only some disabilities require specialized assistance, and that the proper context of special education is "as an ancillary service necessary to a primary goal – academic and vocational instruction for independence and adult life" (p. 113). The debate about educational program provision and setting will be further delineated in the section on the Least Restrictive Environment (LRE) provision.

Another requirement of the IDEA Amendments is that students with disabilities be included in the assessment process with regard to the administration of state or district-wide assessments of student achievement. The implications of this requirement for students with learning disabilities are numerous but, to date, have not been addressed from their perspective:

- What types of testing accommodations will be necessary to support students with learning disabilities and to increase their chances of success?
- How does taking the test in a different setting or with different accommodations make students with learning disabilities feel about themselves?
- What are the social ramifications for students with learning disabilities, in terms of being ostracized by peers, of taking these tests under conditions that differ from their peers?

- How does the challenge of taking tests whose scores are widely discussed and even publicized affect the self-esteem of students with learning disabilities?

In addition to participating in large-scale assessments, two new requirements were added to the sections [614(d)(1)(A)(vii)(I) and (II)] on the provision of transition services:

- Beginning at age 14...a statement of the transition service needs of the child under the applicable components of the child's IEP that focuses on the child's course of study. This requirement augments the existing requirement which states:

- Beginning at age 16 (or younger, if determined appropriate by the IEP team), a statement of needed transition services for the child, including, when appropriate, a statement of the interagency responsibilities or any needed linkages...

- In addition, "beginning at least one year before the child reaches the age of majority under State law, a statement that the child has been informed of his or her rights under this title, if any, that will transfer to the child on the age of reaching majority..." [614(d)(1)(A)(vii)(III)]

These requirements demonstrate the increasing significance of the student's role within the IDEA amendments. How do these requirements to involve the student beginning at age 14 become operationalized into district practice? The need to include students more actively in long-term planning is evidenced by an overall lack of success on the part of these students in their post-secondary endeavors. In a study examining the adult adjustment of mildly impaired high school graduates, Sitlington, Frank, and Carson (1992) found that only 4% of LD males and 10% of LD females met the criteria for being a "successful graduate," which they defined as: (a) being employed either full- or part-time in a competitive job, a homemaker, a full-time student, or in a job

training program; (b) buying a house, living independently, or living with a friend; (c) paying at least a portion of their living expenses; and (d) involved in more than three leisure activities. The authors suggest that schools need to place a greater emphasis on transition planning, including increasing awareness and advocacy as early as the elementary years. They recommend an approach with three major phases:

1) at the elementary level, a focus on career awareness, student's strengths, potential living/working environments;
2) at junior high school, the goal of acquainting students and parents with adult service providers; exploring employment, living, social and interpersonal options; and
3) at the high school level, gaining access to relevant support service providers and ensuring carryover of school support services to post-secondary options.

Despite IDEA's emphasis on student involvement, we must ask if students are truly included in the planning of their educational program, including the transition process? How involved are students in their program, once it is planned? Jorgensen and Tashie (1996, p. 158) found several major problems with the traditional view of transition. They noted that many high school students with disabilities do not have access to typical school experiences – such as classes, extracurricular activities, or graduation planning. Currently, they are not being supported to become fully participating members in those very classes and experiences that could assist them in developing their future goals. How will this

IDEA mandate serve to ensure that districts truly involve students in the IEP/transition planning process? Will they simply give the law "lip service" by inviting students to attend their IEP meeting in the role of a passive onlooker? What role do students believe they should play with regard to developing an educational plan that will successfully prepare them for post secondary life? There is little research to date with this focus on student involvement and self-determination.

Least Restrictive Environment (LRE)

Nowhere is the intensity of debate between special educators as fierce as in the discussion of what comprises the least restrictive environment, or LRE. At the heart of the arguments lie the differing philosophies of parents, practitioners, and researchers, some of whom believe that special education students need to have available to them a full continuum of program options, and others who contend that any program that takes place in a setting other than that of the general education classroom is undemocratic in nature.

The "least restrictive environment" principle states that each child must receive an appropriate education designed to meet his or her needs while being educated with nondisabled peers to the maximum extent possible. Specifically, the law requires each State to ensure that

> 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 regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily [612 (a)(5)(A)]. (Twentieth Annual Report to Congress, 1998)

There exists a faction of practitioners and researchers who hold that this LRE provision mandates the availability of a full continuum of programs and services to meet the needs of special education students. This continuum, they contend, is comprised of seven alternative settings ranging from the most restrictive, such as a separate hospitalized or residential school setting, to the least restrictive, such as receiving special education support through ancillary services provided within the context of the general education classroom (Brauen, 1991; Vergason and Anderegg, 1992). Such researchers argue that specifically excluding any level of a full continuum of services equates to the "functional exclusion" that occurred prior to the passage of PL 94-142. They disagree with the beliefs of inclusionists, that LRE mandates that all special education students be educated in general education classroom settings, and interpret the LRE requirement as intending only to uphold "an instructional climate designed to provide the free appropriate public education that will teach skills needed to facilitate the handicapped person's participation in society as an adult" (Vergason and Anderegg, 1992).

Lieberman (1992) also argues in support of maintaining a full continuum, stating that, while inclusion may be appropriate for some special education students, others will be unable to have their needs met in the general education classroom setting. While Lieberman upholds the need to maintain the continuum, he supports the regular education initiative (REI), advocating general education placement as much as possible for each individual student. He denies that this equates with full integration, which he believes is not possible given the current

standards and lack of responsiveness of the general education classroom to individual needs and circumstances:

> Individualization in regular classrooms is quite a dead issue and has been for years. The barrage of curriculum materials, syllabi, grade-level expectations for performance, standardized achievement tests, competency tests, and so on, continue to overwhelm even the most flexible teacher. Individualization calls for child-centeredness, and child-centeredness has been on the run since the 1960's (p. 15).

Several researchers (Brown, 1979; Grolnick and Ryan, 1990; Kulik and Kulik, 1982; Schunk, 1989; Strang, Smith and Rogers, 1978; Zigmond et al., 1995) have done studies that support the practice of educating special education students in traditional resource room and categorical "pull-out" programs, and that counter arguments by full inclusionists that such programs are undemocratic in nature and harmful to students. While supporters of inclusionary programs contend that special education students in pull-out programs suffer from stigma, alienation from peers, watered down curriculum, and exclusion from the instruction and activities that take place in the general education classroom, these researchers have found that many special education students learn best in such pull-out settings.

Zigmond et al. (1995) reviewed a variety of studies faulting special education pull-out programs, and found most of them methodologically flawed (they compared populations different than those about which they drew conclusions; they had inconsistent conditions) and inconclusive. Their own meta-analysis of efficacy studies of pull-out special education programs versus regular classroom services found a modest academic advantage (.29) for LD students

who received instruction through special classes over those who remained in regular classes.

A variety of studies evaluating the effects of ability grouping, modeling, self-efficacy, and social comparisons among multiple reference groups support the findings by Zigmond et al. Brown (1979) determined that lowered self confidence resulted from watching others, with whom one identifies, fail. Such low perceived efficacy "in turn, may lead people to shun activities and fail to exert the effort necessary to acquire essential skills. Such vicarious experiences could have all the deleterious effects commonly associated with avoidance patterns of behavior, in which one's potential efficacy is not adequately tested and hence not fully developed" (p. 108). Such findings lend credibility to the recommendation to provide special education students with small-group instruction by ability.

Schunk's (1989) study on self-efficacy and cognitive skill learning supports Brown's findings. Schunk concluded, "Students frequently compare their performances with those of their peers. Students may feel more (less) efficacious when they believe they are accomplishing more (less) work than most of their peers" (p. 16). He maintained that, for students with learning problems, other students with similar problems, but who have mastered skills, may make better models than non-disabled peers; "Observing similar peers successfully perform a task can raise self-efficacy in students because they are apt to believe that, if the peers can learn, they can also improve their skills" (p. 20).

In a multiple group comparison study, Grolnick and Ryan (1990) came to a similar conclusion. Their study examined the self perceptions, motivational

orientations, and classroom adjustment of children with LD, matched IQ non-LD, randomly selected non-LD, and low-achieving students, and concluded that "...there may be advantages of LD placement for self-concept, insofar as placement may address existing problems or create a different reference group for social comparison" (p. 177).

Studies by Kulik and Kulik (1982) would support such a recommendation. The findings from their meta-analyses of 52 studies of secondary level students revealed that students in grouped classes developed more positive attitudes about themselves and toward the subjects they were studying than did students in ungrouped classes. Strang, Smith, and Rogers (1978) studied the social comparison among students with multiple reference groups, particularly handicapped students both before and after they were mainstreamed. They found that the situation that proved to be most positive for such students was a partial day in special education classes and partial day in general education, and attributed this finding to the fact that this arrangement provided these students with multiple reference groups from which to draw self-comparisons.

Despite these findings, many in the field condemn the provision of segregated programming and continue to exhort the benefits of fully inclusive programs. In 1992, the state of Michigan charged a committee comprised of representatives from the State Department of Education, public school officials, teachers, parents, and related service providers with the task of developing recommendations for needed changes in policy, funding, and legislation to

assure the availability of an inclusive education option for students with disabilities in Michigan. They defined inclusive education as

> The provision of educational services for students with disabilities, in schools where non-handicapped peers attend in age-appropriate classes under the direct supervision of general education teachers, with special education support and assistance as determined appropriate through the individualized educational planning committee (IEPC)(p. 1).

In reviewing the existing system, this committee found that the "label-and place" categorical mentality was pervasive and often served to exclude students with disabilities from access to opportunities available through general education. Their analysis found that

> Separate categorical labeling and funding rules have created a free-standing, second, parallel, and somewhat fragmented system within the schools. Co-existing alongside general education, this second system is an entity with its own administrators, budgets, departments, inservice education facilities, policies, procedures for student discipline, methods for parent involvement, etc. (Final Report of the Inclusive Education Recommendations Committee: Findings and Recommendations, 1993, p. 16).

A host of parents, practitioners, and researchers (Ferguson (1996), Gartner and Lipsky (1990), Jorgensen (1996, 1998), Lamb (1997), Lipsky and Gartner (1989, 1992, and 1997), Mehan, Hertweck, and Meihls (1986), Oakes and Lipton (1990), Pugach (1992), Stainback and Stainback (1992), Villa and Thousand (1995), and Ysseldyke, Algozzine, and Thurlow (1992), among many others) agree that the current system, based on a medical model of diagnosis, labeling, and prescriptive teaching, serves to perpetuate separate programming. Among the practices they call into question are the overidentification of ethnic minorities; the necessity of labeling students to "fit" into certain programs; overly segregated settings; and escalating costs that are eating away at general

education funds. They point out that special education teachers do not utilize "substantially different instructional methods" based on individual needs (Lipsky and Gartner, 1997), and contend that special education programs limit curricular options for students based upon their disability label.

Inclusionists maintain that the only truly democratic option is to educate all children together; that in fact, as a social institution, schools should be obligated to uphold the very tenets of democracy, including a "belief in the individual's worth, equality of opportunity, freedom of thought and faith in reason" (Ysseldyke, 1992, p. 34). Oakes (1990) asserts that, despite this obligation, existing school cultures are not conducive to inclusive education:

> Regular classes are frequently inhospitable to children with special needs. Most educators and policymakers do not feel able to accommodate children with special needs in regular classrooms. Their first inclination has been to provide special help outside regular classes. Some see disabled students as so fragile that they need protection from regular classroom pressures. Another, usually unstated, motive for separation may be to protect regular students and teachers from children who are different. Those who are not accustomed to being around the disabled may become embarrassed, distracted, and afraid (p. 176).

Reynolds (1975, p. 3) believes that if we fail to acknowledge and deal with such entrenched patterns of existing prejudice, many children will be subjected to painful and frustrating educational experiences. Clark (1990, p. 261) echoes this sentiment, adding that it is a "fundamental responsibility of teachers...to create and sustain conditions that will promote learning for each and all of their students....This is both a pedagogical and a moral imperative."

The need to reexamine critically the ways in which we have traditionally supported special education students was emphasized in a study of

postsecondary LD adults (Murphy, 1992). Murphy interviewed 49 adults with learning disabilities, all of whom were presently attending or had graduated from a 2-year or 4-year college, community college, or technical training program, and found that many of them harbored strong feelings about their earlier years of education:

> Besides the stigmatizing aspects of segregation, special placements separated LD students from their friends, disrupted their daily schedules, and often did not provide the help they needed to progress academically....Thus students were often saddled with both the stigma of special placements and continuing academic problems. It is little wonder that special placements in elementary and high school were frequently and consistently cited as the most aversive consequence of being labeled (p. 121).

Inclusionists believe that the needs of different children to learn by different methods and in different places should lead us to consider "challenging the logic of attaching services to places" (Ferguson, 1996) by reinterpreting the concept of "continuum" from its present connotation, as a continuum of physical locations, to rather a broader definition encompassing a variety of types and intensities of services delivered in a variety of locations, most preferably the general education classroom. Lipsky and Gartner (1997) accuse the present interpretation of confusing the intensity of services with a physical setting (more intensive services are in more restrictive settings). They believe that there is an expectation for students to "prove their readiness" for an integrated setting rather than a presumption that such a setting should be the norm. The present definition, they state, incorrectly places more emphasis on the setting than on necessary supports and services. The Final Report of the Inclusive Education Recommendations Committee (1993) incorporates this shift in focus to

necessary support services in their definition of "continuum" as "full-time general education with support to full-time special education in a general education building" (p. 35).

So pervasive is the traditional system that many believe a major paradigm shift to "inclusion," the provision of services within the least restrictive environment -- the general education classroom -- can only truly succeed with a total restructuring of schools. The move toward inclusion should not be considered as a "special education reform," but as falling within the purview of more global school improvement efforts. Ferguson (1996) conceives of inclusion as "a process of meshing general and special education reform initiatives and strategies in order to achieve a unified system of public education that incorporates all children and youths as active, fully participating members of the school community" (p. 17). Lipsky and Gartner (1997) state,

> What is needed, then, is not a tinkering at the margins of IDEA but rather a fundamental change of the existing dual, failing, and costly special and general education systems. Such change involves redirecting the focus of the IDEA debate toward the broader matters of educating students in a unitary system that will prepare them to participate in society. What is required is reconfiguring IDEA to support a strategically altered educational paradigm – one that more equitably addresses disability, student learning, and the nature and purposes of schooling in a democracy preparing for the 21st century (p. 69).

This view, that inclusion reform needs to be part of a broader restructuring effort, has been echoed by many (Ferguson, 1996; Johnson and Pugach, 1992; Kugelmass, 1996; Lamb, 1997; Lipsky and Gartner, 1989, 1992, and 1997; Oakes, 1990; Pugach, 1992; and Walker, 1987). The Final Report of the Inclusive Education Recommendations Committee (1993) asserts,

> School improvements in general education, as part of Public Act 25, must provide the umbrella effort for improving instructional practice for all students including those with disabilities. Dual and parallel systems must be merged in favor of a unified system (p. 35).

How is this "restructuring" to be brought about? Many who promote inclusion believe that the key to successfully unifying special education and general education is collaboration between both groups of professionals. Special educators must be available to provide support to special education students within the context of the general education classroom setting as well as to general education teachers who must learn how to adapt curriculum and pedagogy to the diverse needs of their students. Lipsky and Gartner (1989) point out how inclusion without support can lead to unsuccessful outcomes:

> The reform focus on so-called raised standards without a commitment to provide necessary additional services and assistance results in an increase in failures and those labeled "school dropouts." And those not forced out by failure - ascribed to the student but more often the school's – may be "pushed out" by the school culture that is hostile to many students (p. 152).

Oakes and Lipton (1990) agree that many children currently labeled as handicapped actually require only a little extra support in the form of "time, attention and tolerance" (p. 178) to be successful in the general education setting. In the provision of such support, Johnson and Pugach (1992) believe it is imperative to move away from the hierarchical model, where the special educator is seen as the "expert," to a multidimensional "collegial" model consisting of four possible roles: prescriptive, informative, facilitative, and supportive. The ability to meet the needs of students within inclusive classrooms depends upon the ability

of educators to collaborate successfully, recognizing and overcoming traditional barriers.

In addition to a collaborative model, Lipsky and Gartner (1992) affirm that the climate in the classroom must be child-centered, oriented toward the needs of the students. They call for classroom practices that put an end to sorting and tracking, focus on providing help to all students who need it, and incorporate multiple intelligences into instruction. Kugelmass (1996) emphasizes that classrooms need to reflect processes that are participatory and democratic, and calls for a "pragmatic and progressive" curriculum based on the learner-centered educational principles put forth by Dewey.

Such efforts to unite both systems have already begun (Lamb, 1997), with inconsistent results. Funding inequities continue and are often at the root of programming decisions (Fafard, 1995). The presence and participation of handicapped students within the general education classroom still falls short of that envisioned, while many students who are "included" still seem set apart from their classmates (Ferguson, 1996). Despite the numerous programs put into place since PL 94-142, "Many secondary-age students with learning disabilities leave the educational system before they can take full advantage of these programs. Reports of a serious dropout problem in the population of students with learning disabilities are surfacing in both urban and rural communities" (deBettencourt, Zigmond, and Thornton, 1989, p.40).

Regardless of the nature of the programming, the fact remains that many students with learning disabilities do not complete high school and, if they do,

they remain largely unprepared for postsecondary life. Research cited here has attested to the rift that has developed between educators adhering to two differing philosophies; what neither argument has taken into account are the beliefs, feelings and perspectives of the students whom they serve. The importance, impact, and stigma of identification, labeling and separate placement have been touched upon in the research presented here, but few studies exist that inquire after the student perspective, even in child-centered approaches. The importance of having "voice," being in "control," having the power of "self-determination," and the consequences in terms of motivation and performance when these are denied will be discussed next within the context of student participation in the IEP process.

Parent and Student Participation in Decision Making

The Twentieth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (1998) states that

> IDEA strongly encouraged the participation of and communication among all parties who have a vested interest in the education of students with disabilities. On the one hand, parents have always been important players in the special education process, and their involvement is crucial to successful results for students. On the other hand, the language inviting student participation has become stronger with the past two reauthorizations of IDEA, particularly in the area of transition.

The law now requires that students, beginning at age 14, must be invited to participate in their IEP meeting. The law "acknowledges that if students are to develop into independent, productive adults and become increasingly responsible for their behaviors and accomplishments, they need to acquire the skills that promote decision making" (Twentieth Annual Report to Congress,

1998). Until now, little has been done to ensure that special education students are involved in the process of developing and implementing their individualized educational plans. To date, this has been largely the responsibility of adults, particularly teachers, with parental input. The reasoning behind the addition of this new requirement is well founded in research and forms the basis of this study.

Much research has been done that demonstrates the impact of perceived control and the individual's freedom to choose on their motivation, psychological, and even physical well-being. Steiner (1979) describes "control" and "choice" as two differing experiential states that are difficult to study and measure empirically. He defines "control" as the feeling a person experiences when he or she (rather than other people, luck, or unmanageable forces) determines whether desired outcomes will be received. A person experiences "choice" when he or she is the agent who decides which of two or more options will be accepted. Steiner differentiates between three kinds of choice: evaluative, discriminative, and autonomous. In evaluative choice, the person must evaluate or decide if any of the choices are good ones. In some instances, as in the movie "Sophie's Choice" in which a mother must decide which of her two children she will sacrifice, none of the alternatives may be viable.

In discriminative choice, the individual must discriminate between alternative choices by distinguishing how much better one alternative is compared to another. The degree of choice is dependent upon the perception of

the desirability of each alternative. There may be a large margin of difference, rendering the choice a "no-brainer"-- hardly a choice at all.

Two or more alternatives, at once both complex and different from one another, comprise autonomous choice. One must decide how important each one is along a variety of dimensions. Here, "the individual's idiosyncratic preferences guide the evaluative process, and the individual, rather than the obvious qualities of the options, appears to determine the decision" (Steiner, 1979, p. 24). Steiner believes that this represents "choice" in its truest form, offering the individual the greatest autonomy; they are in charge of comparing and assessing the various assets and liabilities of the available alternatives, and choosing among them.

DeCharms (1979) differentiates even further in his discussion on the concepts of "personal causation" versus "perceived control." He states that "perceived control" is a highly visual concept, involving perception. The person is passive: a thinker, perceiver, attributor, reactor. He asks, "Can we really *see* or *perceive* control?" DeCharms believes, instead, that one *experiences* being "in control"-- it is kinesthetic in nature. In his interpretation, the person is either the "origin" of the action-- an agent, a doer -- or the recipient of the action of others, a "pawn". He uses the term "personal causation" to connote these origin/pawn dimensions.

DeCharms believed in studying the concept of control or personal causation within a meaningful, practical context. He conducted decades of research in elementary classrooms, assessing the achievement levels of

students along the variables of origin ideas (goal-setting, self-directedness, ownership of behavior) and pawn behaviors (passivity, lacking goals, other-directedness) as they were reflected in the students' short stories. From his findings, he concluded that "Children who experienced personal causation positively as origins...achieved more than those who experienced school as a pawn atmosphere" (deCharms, 1979, p. 34).

DeCharms also did studies of students in the sixth and seventh grade who had been trained in personal causation and origin-type behavior. Follow-up studies years later showed that more of these students went on, in significant numbers, to graduate, than did untrained students. In addition, trained students also held more concrete plans for the future.

Ryan and Grolnick (1986) conducted a series of studies evaluating the significance of students' perceptions of classroom environment along variables of encouraging autonomy versus exerting external control. They examined the relationship of classroom climate to self-related constructs and found that the more "origin" the climate, the higher the students' perceived self-worth, cognitive competence, internal control, mastery motivation, and lower the perceived control by unknown sources or powerful others. When they controlled for "between class" effects, they learned that these relationships were primarily due to individual differences within the classroom rather than the average classroom differences. They concluded that a key factor is the functional significance or meaning of the environment to each individual rather than the classification of the environment per se (p. 557). These studies by Ryan and Grolnick did not,

however, examine the factors which might produce variance in how individual children view their classroom environments along the origin-pawn dimension, something future studies might consider. The authors contend that the findings from this study lend "further support to the growing literature suggesting that the experience of autonomy is a significant contributor to children's school-related and general adjustment, and an important target for applied psychological research" (p. 558).

Bastien and Adelman (1984) also investigated this concept in their study of 55 adolescents in a residential treatment facility. They used a structured questionnaire to interview these adolescents to determine their perceptions of choice, attitudes toward the program, and evaluation of their progress in treatment. They found that "perceived choice about remaining in the program was found to have a significant relationship to progress in treatment" (p. 177). Although this sample differs qualitatively from samples drawn from public schools (the adolescents were admitted to the facility due to legal or psychiatric involvement), the results of this study support other research: "...the findings are consistent with a growing body of literature that stresses that perceptions of choice, and events that lead to such perceptions, are important factors, influencing behavior and behavioral changes" (p. 178).

In her studies of elderly nursing home residents, Langer (1983) discovered a link between the loss of control, even if it was only perceived loss, and a decline in the emotional and physical well-being of the residents. Through her research, she determined that individuals often "give up" when they believe they

no longer have any control over things (like daily routines, meals, rooming arrangements, and activities) that are important to them. Such a real or perceived loss of control led to stress, a state of increased passivity/dependency, incompetence, and even symptoms of reactive depression. Langer documented several aspects that served as subtle cues of incompetence to the residents, including the act of institutionalization itself, the label of "nursing home patient," the extra care, help, and attention received as a result of this living arrangement, and being treated as one of a "class" of individuals (elderly or infirmed) without regard to person-specific factors.

These findings are important to this study when one considers the possibility of drawing parallels between residents in a nursing home and students in special education classes. Such similarities may include the act of being identified and labeled as "different" (LD); placement, without being asked, into special education classes; being treated as someone who needs extra help; being treated differently, as a member of a distinct class of people – the handicapped; and being viewed more as a "label" than as an individual. If one can, in fact, draw such comparisons, one can also see the similarities between the passive dependency largely characteristic of nursing home residents and the amotivational state so often ascribed to learning disabled adolescents. The need to investigate the linkage between personal causation, choice, self-determination, and motivation in the high school population of students with learning disabilities is further emphasized.

Deci (1995) defines human behavior and experience as a dialectic between a person and the environment:

> ...the interaction (and potential opposition) between the active organism striving for unity and autonomy and the social context that can be either nurturing of or antagonistic toward the person's organismic tendencies. Synthesis occurs when there is enough in the social context so that the natural, proactive tendencies are able to flourish. But in the absence of adequate supports, not only will intrinsic motivation be undermined, but so too will the development of a more integrated or coherent sense of self (Deci, 1995, p. 83).

He distinguishes between two types of internalization, introjection and integration. Lack of an autonomy-supportive environment may lead to what he terms "introjection," which occurs by "swallowing a rule whole, rather than digesting it" (Deci, 1995, p. 94), and does not equate with true autonomy. We see evidence of this type of behavior in compliant but uninvolved students, who go through the motions of school. The other form of internalization, "integration," takes place when rules are "digested" and internalized as being consistent with one's own values. Integration, the result of an environment supportive of self-determination, often leads to true autonomy:

> People's need for autonomy, their need to be a causal agent in managing themselves, provides the energy for integrating (rather than just introjecting) a regulation. Thus, although the needs for relatedness and competence can motivate introjection, it is the need for autonomy that champions the integration of a value or regulatory process into one's *self* (Deci, 1995, p. 94).

Deci believes that in order to promote autonomy, we must relate to others, "our children, students, and employees – as human beings, as active agents who are worthy of support, rather than as objects to be manipulated for our own

gratification. That means taking their perspective and seeing the world from their point of view as we relate to them" (p. 100). He asserts that

> As socializing agents – parents, teachers, and managers – it is our job to encourage others to do many things they might find boring but that allow them to become effective members of society. Actually, our job goes beyond just encouraging them to do the activities; it's more challenging than that. The real job involves facilitating their doing the activities of their own volition, at their own initiative, so they will go on doing the activities freely in the future when we are no longer there to prompt them (Deci, 1995, p. 92).

Deci (1995) advocates for the incorporation of autonomy support into the policies and practices by which we operate our governments and institutions:

> When decision makers understand that people can be motivated in either autonomous or controlled ways, and that systems, organizations, and individuals can promote motivation in either autonomy-supportive or controlling ways, they can create policies that are more oriented toward supporting autonomy than toward controlling behavior (p. 60).

He points out that the critical question to be answered is "How can people create the conditions within which others will motivate themselves?" (p. 10), and suggests ways to facilitate autonomy that include providing choice, encouraging self-initiation, experimentation, and responsibility. In schools, this would mean taking into account the students' perspectives, looking for other than the traditional, controlling, hierarchical ways of carrying out the agenda, and involving students in a shared decision-making process.

In a study on facilitating internalization in a paired associate learning task, Deci, Eghrari, Patrick, and Leone (1994) identified three contextual events that promoted integrated internalization: (a) providing a meaningful rationale for the task, (b) acknowledging the behaver's perspective, and (c) conveying choice rather than control. They suggest that an environment structured in this way,

conducive to self-determination, will bring about an increase in intrinsic motivation and perceived self-competence. The effect is cyclical: "The fullness of intrinsic satisfaction associated with doing well necessitates being self-determining, and the experience of being self-determining allows one to have some failures without their negatively affecting intrinsic motivation" (Deci, 1980, p. 44).

Adelman and Taylor (1983, p. 391) have identified the components and mechanisms of classroom programs which serve as the foundation for a motivationally-oriented environment. These strategies include

- a wide variety of options regarding the content and process of programs for students in order to capitalize on each student's motivational and developmental status;
- a continuum of structure, including communication, support and guidance;
- active decision making by the student relating to all major decisions, serving to increase his or her perception of commitment, control and personal responsibility;
- informal and formal conferences, in order to increase the student's perception of his or her role in making choices, negotiating and establishing arrangements;
- contractual agreements – meant to clarify "intrinsic justifications, personal choice, and responsibility, and as a means of further enhancing commitment and motivation";

- ongoing assessment and formative evaluations to increase the learner's knowledge of his or her own role in monitoring progress and in evaluating and developing optimal programming to increase progress; and
- expanded classroom limits and non-authoritarian teaching style (including the elimination of nonessential rules and avoidance of arbitrary and coercive actions).

Thus, for students with learning disabilities, whose school histories have been steeped in academic failure, the ability to be self-determining, to take on an active and supported role in their educational planning, may lead to increased motivation and performance.

Environments that do not take these factors into account, that continue to coerce and control, to ignore students' perspectives, may have an opposite effect, that of engendering counter control and defensiveness. Moyer (1979) uses the term "counter control" to describe behaviors that are "resistant," "noncompliant," "passive-aggressive," "oppositional," or "negative" in nature. Phares (1979) found that the attribution of one's failure to external causes allows one to evade taking any personal responsibility. Using Rotter's (1966) Internal-External Control Scale, Phares found that "Externality may act as an adequate defense against failure, but very high scores toward the external end may suggest, at least in our culture, a defensiveness related to significant maladjustment" (Phares, 1979, p. 197).

Failure to include students with learning disabilities, who may be suffering

the stigmatizing effects of an undesired label, separation from non-disabled peers for part or all of their school day, differential treatment in terms of their class membership, and lowered expectations by others of their abilities, as active participants in their own programming decisions may well lead to the types of behaviors described above. Deci and Chandler (1986) state that current research in the field of learning disabilities largely ignores these factors, focusing instead on the basic issues of defining learning disabilities, locating their cause(s), determining how they can be prevented, and deciding how they should be "treated." They found that traditional definitions lack consideration of the role of emotional/motivational variables as causes or factors that may exacerbate neurologically based deficits. They advocate for a treatment approach that incorporates what they call a "macroperspective" – sensitivity to the general and individual needs of all children, and adoption of a motivational perspective that "promotes a more holistic, active-organism approach to the education of children in general and of LD children in particular" (p. 589).

The school environment of the LD student is typically characterized by rewards, deadlines, surveillance, threats, and competition, all of which may serve to restrict self-determination. In addition, such amotivating events as repeated failure and unpredictable/uncontrollable outcomes are highly present in their daily lives. Deci and Chandler note six factors that are important to promoting self-determination: optimal challenge, autonomy, competence, involvement, rationale, and acknowledging feelings. They believe that the behavioral/operant perspective that is widely utilized in research within the LD field is far too narrow

to be useful as an organizing theme. They suggest, instead, that future inquiries and interventions focus on the socio-emotional aspects of LD, incorporating the psychological constructs of self-determination, competence, and relatedness underlying motivational theory. Yet, to date, very little research involving the importance of such constructs has been done with this population. A review of these few studies follows.

Prompted by her belief that governmental reforms largely discriminate against children by arbitrarily basing rights on age alone, Margolin (1982) studied children's views of their selected self-determination rights. She found that "children's attitudes concerning their rights have received little attention in scholarly research and popular media" (p. 97). Polling children to determine their views, Margolin found that support for their right to self-determine increased with age, with younger children preferring the protection and nurturance of adults in situations where an improper decision could lead to direct harm. Margolin accuses child advocates, both those she terms "protectionist" and "liberationist," of believing that they know what is best for children without ever asking children in any meaningful, systematic way, for their views. Margolin affirms

> Asking children for their view on policies which affect them could add a new dimension to policy-making and strengthen rather than undermine two strongly-held values in this society: constitutionally protected civil rights and special beneficence toward children (p. 99).

The 1989 study conducted by Taylor, Adelman, Nelson, Smith and Phares was founded on a similar premise, the belief that minors, including those in special education programs, can voice clear perceptions about their sense of control in school and clinical settings. "Control" was defined as "the degree of

freedom one expects to have over the processes that one believes must be pursued in order to accomplish particular outcomes" (p. 439). Subjects of the study were students, ranging in age from 9 to 19, from three different settings: those in an experimental special education program focused on enhancing students' perceptions of control; students in public school special education programs; and students in public school regular education programs.

Students were administered two different surveys designed by the authors to ascertain (1) how important it was to them to have control (Perceived Importance of Control in School Survey – PICSS) and (2) how much control they believe they actually had (Perceived Control in School Survey – PCSS). On both combined and subgroup analyses, they found a pattern demonstrating that older students were higher in their ratings of the importance of control. While students in the experimental special education program (focused specifically on increasing opportunities for self-determination) responded, quite understandably, that they perceived they had a higher degree of control than did the other special education group, both groups indicated a high value for control. In summary:

> The present findings indicate that although special and regular education students differ significantly in their perceptions of control related to areas of functioning at school, such youngsters are quite comparable in the areas over which they value having control. Their responses also indicate that they value control at school quite highly (p. 442).

Taylor et al. recommended further study in this area, including studies that "explore the impact of situation-specific perceptions of control vis-à-vis valued areas and the modification of such perceptions across a wide range of child adolescent populations" (p. 443).

A special education resource teacher described how she teamed up with a university researcher in a collaborative research venture to study the effects of coaching elementary special education students "to recognize, interpret, and respond to their regular class surroundings with strategies that would give them a feeling of power or influence to succeed despite their learning disabilities and independent of my 'help'" (Davis and Ferguson, 1992, p.126). Acknowledging the difficulties inherent in stepping back to allow the students to define and select study skill strategies they thought would work best for them, Davis conceded that this new emphasis sometimes created interesting discussions and negotiations. She found herself becoming more attuned to seeing situations anew from the students' perspectives:

> My listening skills quickly improved, hearing even the subtle criticisms and fragile satisfactions. Sometimes I found it difficult to refrain from identifying "the problem" they were facing. I resisted, however, in favor of helping them "find" the problem for themselves. In the process, I learned to better appreciate *their* problems from *their* perspective (p. 131).

Davis admitted to being "taken a bit aback at their assertiveness," but stated that, upon reflection, she realized "that their newfound power to influence and change features of a classroom environment might suggest to them that they could have similar influence in other arenas that affected their school lives" (p. 133). She continued to work with students, advocating that they take on an increased role in their IEP meetings, and summarized their perspective:

> They complained about not being routinely invited to participate, questioned the presence of so many adults, and admitted feeling awkward talking to adults about their needs and preferences. One student feared that "I'm just a kid. No one cares what I have to say." Another cynically queried, "You (adults) already have your minds made up so why should I tell you what I think?" (p. 134).

A student interviewed for the National Study of Inclusive Education (1995) articulated a similar point of view:

> My parents had to be involved to insure that I would receive a proper education. And I learned from that example. I learned that the best advocate I have is me; I have to express my own needs. All students have to be aggressive; they have to be articulate. That's especially true for disabled students (McKeithan,T.L., 1995).

Students with learning disabilities may not have the prerequisite skills necessary to self-advocate successfully. They may be reluctant to participate in meetings they perceive as dominated by adults. A study conducted by Patricia Phillips (1990) focused on assessing the effectiveness of an intervention program designed to enhance students' ability to self-advocate. Participants were 15 ninth and tenth grade students with learning disabilities from a comprehensive four-year high school. Students responded to standardized open-ended interview questions after participating in the first step of a 4-step self-advocacy plan. The findings suggest that such a self-advocacy plan is effective in "increasing students' awareness of the vocational and academic services they qualify for; clarifying their perceptions of their roles as learners and individuals with LD; increasing their understanding of LD as a condition that has certain general characteristics; and developing their awareness of career and educational opportunities" (p. 466). Although this study is informative with regard to providing valuable insights for enhancing student participation, the findings are limited for a number of reasons. The study was based on a very restricted sample of a small number of students from a single, middle class setting. Although the self-advocacy plan was a program intended to enhance the self-efficacy of LD

students, it was designed for these students by adults, with no student input. In addition, no pretest measure was taken to reflect the students' status prior to participating in the program.

Adelman, MacDonald, Nelson, Smith and Taylor (1990) found contrasting results in their study designed to assess a similar intervention strategy. As part of their ongoing research exploring the relationship between motivational factors and intervention efficacy with LD children, these researchers studied the effects of a short-term, experimental, cognitive-affective intervention intended to enhance motivational readiness for participating in educational decision-making conferences. Their sample consisted of 85 students, ages 5 to 18, who were diagnosed with learning disabilities. The students were assigned to one of three treatment groups: preconference intervention, placebo, or non-intervention conditions. From their findings, these researchers concluded that skill training had a limited impact on student participation and decision making.

This study differed from that done by Phillips in that the intervention strategy in Phillips' study was long-term; the student participated in four different phases of instruction, beginning in his or her freshman year and continuing through the senior year of high school. During this time, students were involved in discussion groups whose topics included the concept of a learning disability; information about specific learning disabilities; school and social relations issues related to learning disabilities; specific learning strengths and weaknesses of the students; successful people who have learning disabilities; legislation regarding learning disabilities (P.L. 94-142); the availability of postsecondary assistance;

and the responsibilities of the Division of Rehabilitation Services (p. 467). The intervention strategy employed by Adelman et al consisted only of a single, 5-to 15- minute session designed to "give the students permission and encouragement to participate in the conference, to discuss and briefly rehearse participation strategies and to induce personal responsibility for participation" (p. 173). The comparability of both strategies is limited therefore by the difference in both the scope and depth of each. The authors of both studies reiterate the importance of additional research studying the effects of enhanced motivation on the participation and involvement in educational decision-making of students with learning disabilities.

The need for such research is again supported by Murphy (1992). In his qualitative study involving interviews with 49 LD adults, Murphy found similar themes underlying their responses. Having completed either a two- or four-year college or technical training program, these LD adults reflected on the personal pain, difficulties and frustrations brought about by their diagnosis, labeling and special education programming. Murphy found that, in order to avoid the stigma of a special class placement, these students admitted to "manipulating" their instructors and avoiding detection as inferior students. He strongly invoked the need for further research in this area:

> Examining the ways people with learning disabilities define themselves and their circumstances will enable us to better understand important referents for individual conduct. Moreover, by studying how individuals manage the educational, social, familial, and vocational demands of their everyday lives, we can more thoroughly uncover the adaptive and compensatory strategies they employ (Kavale, 1988), and more critically analyze existing theories, treatments, and public policies directed toward people with learning disabilities (p. x).

Summary

The IDEA mandate that parents and students be invited to participate in the decision-making process appears to be well-founded in research. The ways in which schools seek to encourage such participation need further exploration. Are parents and students truly active participants in the IEP process, or do all the adults truly "have their minds made up" – giving only the appearance of complying with this law?

A study that seeks to gain the perspectives of LD secondary students regarding their involvement in their program development and implementation and to discern the factors that influence such involvement seems to be the next natural step. The importance of environments which support self-determination, personal causation, and autonomy for motivation and well-being has been clearly documented. The amotivational state that develops in the absence of such supports has also been well researched. The little research on these subjects that does exist with regard to students with learning disabilities seems to clearly point out the relevance of this area for further study. In exploring these issues, this study adds to the body of existing research concerning the factors that influence the involvement of secondary students with learning disabilities in the development and implementation of their individualized educational plans. The knowledge gained from this study may potentially influence the future development of policies and programs intended to address the needs of secondary students with learning disabilities.

Chapter 3

METHODOLOGY

Introduction

The purpose of this study was to examine the factors that shape students' involvement in the educational decision-making process, as specified by the IDEA mandate. In particular, this study explored the variables that influence the ways in which students with learning disabilities become involved and participate in the development and implementation of their individualized educational plan (IEP), and how they mediate between IDEA policy and district practices to access special education services. The 1997 reauthorization of the IDEA now requires student involvement in the decision-making process beginning no later than age 14. The ways in which students perceive that their school encourages and creates the environmental conditions that foster their participation was the subject of this research.

This chapter explains the methodological approach selected for this study, the site of the study, the population, sample size, and composition. The collection of the data and its subsequent coding and analysis are also discussed. Finally, the limitations of the study will be presented.

Methodological Approach

It was the intent of this study to examine, from the students' perspectives, student participation in the decision-making process, as mandated by the Individuals with Disabilities Education Act (1990) and as reiterated through its 1997 reauthorization. The case study is one method that is conducive to this type

of study. Case study methodology is particularly appropriate to employ when one is attempting to examine how a particular policy is implemented, and the effects of that implementation on the stakeholders involved. According to Majchrzak (1984),

> Case studies...promote examination of the process by which an intervention or policy action has been implemented (e.g., how was a congressional policy action changed as it was interpreted and adapted by federal government agencies, state government agencies, and, finally, the local service delivery program). This last contribution of case studies is particularly useful for developing recommendations concerning the future implementation of policy options (p.63).

The case study is an excellent means by which to study students within their own environment, the school, and to solicit from them their perspectives as to how their school has developed a climate that supports and encourages their participation in educational decision making processes. According to Majchrzak (1984), case studies "provide for a more complete understanding of a situation's complexity by examining behavior in context" (p.63). Yin (1994) maintains that case studies may be superior to surveys and experimental strategies for explaining the complex causal links in real-life interventions. In defining the situations where use of a case study is recommended, Yin (1994) explains,

> ...the distinctive need for case studies arises out of the desire to understand complex social phenomena...the case study allows an investigation to retain the holistic and meaningful characteristics of real-life events – such as individual life cycles, organizational and managerial processes, neighborhood change, international relations, and maturation of industries (p. 3).

Indeed, several of the research studies that have been conducted on related topics have utilized a case study approach. Margolin (1982) interviewed

children to determine their attitudes about their constitutional rights, and found that, while younger children preferred adult guidance and direction, as children grew older, they felt increasingly stronger about their right to self-determine.

Special education resource teacher, Christy Davis, and university researcher, Dianne Ferguson (1992) also used the case study method to evaluate and report on the effectiveness of coaching students in self-advocacy skills. Working with the learning disabled students in her class, Davis developed her skills as a listener and avid observer of behavior, interviewing her students and watching as they took on increasing responsibility for developing their educational program.

Patricia Phillips (1990) also used case study methodology involving participant observation and interviews in her research involving assessment of a self-advocacy plan of intervention. As part of this study, she investigated the perceptions of 15 high school students with learning disabilities, their parents and resource teachers to determine the effectiveness of an intervention technique designed to increase student self-advocacy skills.

In another case study, Steven Murphy (1992) analyzed the prior school experiences of 49 adults diagnosed with learning disabilities. Murphy conducted interviews with these subjects, all of whom had completed high school and had continued on in either a two- or four-year college or technical training program. From their responses, Murphy was able to uncover several salient themes depicting his subjects' school experiences.

The present study utilized the multiple case study approach to reveal factors that influence the involvement of nine LD high school students in developing and implementing their individualized education plans. Students' stories were documented through interviews that were conducted using an informally structured, open-ended interview protocol. Interviews with students' parents, to elicit experiences from the parents' perspectives, were also conducted using a similar format. Data in the form of information from students' case files and participant observation notes from IEP meetings was also gathered and used to validate student and parent responses. A cross-case analysis was performed to assess salient themes underlying students' and parents' responses. These themes were analyzed within the framework formed by the five major principles of the IDEA (Individuals with Disabilities Education Act), using the theoretical lenses formed by self-determination and labeling theories.

The Site, Population and Sample

A sample of 9 students with learning disabilities was selected from the population of special education students attending Great Lakes High School, a "Class A" school of approximately 1,700 students. Great Lakes is a sprawling, primarily white, middle class, suburban school district of 5,400 students, located in mid-Michigan. Parents of Great Lakes students are predominantly professionals or skilled workers with a far lesser percent falling into the working class category; nearly 90% of Great Lakes graduates go on to four-year colleges or universities.

Great Lakes High School was selected as the site for this study for several reasons. My current position as a special education director provided access to students with learning disabilities. The proximity of the school to my work facilitated the process of data collection. I do not believe that there was any conflict between my dual roles as a researcher and a district level administrator as I do not directly oversee the students or evaluate their teachers. I have previously conducted other, less formal survey research within the department and have received cooperative participation from parents and staff. Parents routinely contact me to convey their satisfaction or dissatisfaction with existing programs and services, making dialogue between myself and parents and students a natural phenomenon.

Students with learning disabilities comprise the largest group of students attending Great Lakes High School who are eligible to receive special education services. Great Lakes High School has approximately 150 students who are diagnosed as having a learning disability, using a county-wide discrepancy formula between student ability and achievement (standardized student achievement scores fall at least 20 points below their scores of cognitive ability, which lie in the average range, as determined by the WISC-R or Stanford Binet).

Special education services for LD high school students at Great Lakes High School fall along a continuum, ranging from the least restrictive (full-time general education placement with co-teacher support) to much more supportive and restrictive placements (nearly full-time placement in a categorical classroom for students with learning disabilities). Students come to the high school from two

"feeder" middle schools, encompassing a diversity of special education programs and services.

In acquiring a sample of students for this study, I visited high school special education resource classes to present information about the study to special education students. Students with learning disabilities who were not enrolled in any special education classes (they may have been receiving services in co-taught classrooms, with a general education and special education teacher) were not given this presentation, as I did not want to enter these classrooms to discuss the study and thereby, inadvertently, draw attention to the students who were eligible for special education. Therefore, students requiring a minimum of service, who were the most independent within the population of students with learning disabilities, were not included. Students in the resource classes (up to three hours a day of service) were invited to consider participating. Printed information outlining the study and parent and student consent forms, along with stamped, return envelopes were left with each special education resource classroom teacher.

A total of eighteen special education students, with varying disabilities, indicated interest in being participants and returned the student and parent consent forms. From this group, an initial sample of twelve students with learning disabilities, from grades 9 through 12, and their parents were selected to participate in the study. This number was chosen as a reasonable and manageable sample to interview in the given time period. The sample was

stratified by grade to increase the likelihood that students with a variety of educational experiences were included.

From the initial group of twelve, nine students (five males and four females) and their mothers actually completed the interviews. One student moved away during the course of the year, another became quite ill and stopped attending school, and a third never followed through with the interview. The final sample was comprised of student participants from each gender and grade level, and was believed to be adequate for the purposes of this study. The students who participated in the study (pseudonyms are used in place of actual names) are as follows: ninth graders – Tiffany, Brian, and Heather; tenth graders – Eric; eleventh graders – Jim and Tracy; and twelfth graders – Amanda, Devin, and Tina. Although I discussed the study with both of the parents of each student (when available), in each case it was the student's mother who actually participated in the study. The students came from a variety of socio-economic backgrounds; mothers' vocations included manager of a fast food restaurant (1), bus driver (1), secretary (5), automobile factory line worker (1), and teacher (1). Two of the students, Brian and Tracy, lived with both of their biological parents; the other students lived with only their mother and, at times, their mother's significant other.

Data Collection Tools

Data was collected primarily through the interview process, which began in November 2000 and continued through the 2000-2001 school year. In an effort to solicit their personal stories and individual perceptions, students and their

parents were individually interviewed using an informally structured, open-ended interview protocol. Questions were formulated to prompt students and parents in developing their responses. Students and their parents were asked to discuss their knowledge and understanding of IDEA; their understanding and acceptance of the learning disability; parental acceptance and expectations; the appropriateness of the educational program in meeting their educational needs; their desire and ability to self-advocate; and their involvement in the development and implementation of their individualized education plan (IEP). Interviews, typically lasting anywhere from forty-five minutes to an hour and a half, were audio-taped.

For reliability, students and their parents were offered an opportunity to review a written summary of their own responses and to comment on their content and accuracy. None of the students or their parents chose to exercise this option. In addition, notes were taken during observations from the students' IEP team meetings. These notes were used to corroborate information gathered through the student and parent interviews concerning the student's role and degree of participation in their IEP team meeting. Information from students' files was also collected to establish background information such as initial date of eligibility; previous student attendance at IEP team meetings; parent attendance and expressed concerns in IEP decision-making; past and current special education program placements; recommended accommodations and modifications; supplementary aids and services provided to assist the student with participation in the general education curriculum; and any experiential

programming such as work experience, job shadowing, vocational training, etc. in which the student may have participated.

Several other researchers studying related phenomena utilized a similar approach. Murphy (1992) and a colleague interviewed 49 LD adult participants, asking each a consistent series of open-ended questions. Each interview lasted for an average of one hour and 40 minutes, and followed basic research themes and sub-themes such as early recollections; experiences in elementary, middle, and high school; college experiences; graduate school; employment experiences; family issues; social issues; technical assistance; psychological issues; and adult issues.

In Patricia Phillips' qualitative study, 15 adolescents with LD, ranging from 13 years 8 months to 16 years 2 months in age, were interviewed to determine their perceptions regarding the effectiveness of a systematic, planned intervention program aimed at teaching students to self-advocate within the high school setting. Phillips conducted standardized, open-ended interviews over a two-month period. She also collected additional data in the form of field notes of the students' personal records and school files. As a participant/observer, she facilitated the collection of observational and anecdotal data.

Data Analysis

Student and parent responses to the interview questions were audio-taped and transcribed. Pseudonyms were used to replace actual names of student and parent participants as well as any other individuals mentioned in their responses. A line-by-line analysis of each transcript was conducted. The data were analyzed

in relation to the research questions and coded using a constant-comparative, emergent theme approach. Emergent subthemes, patterns or explanations were then combined into major themes. These methods of data analysis are similar to those utilized by two previously cited authors, Murphy (1992) and Phillips (1990), in research that was closely related to this topic.

Limitations of the Study

The findings from this qualitative study should not be generalized to a larger population due to several limitations. The restricted sample size of nine students, drawn from a population of learning disabled students attending a single high school in a largely middle class, white community, yielded a study whose findings may not necessarily apply to learning disabled high school students in other, dissimilar settings. It was not the intention of this study to produce findings that would generalize to the population of learning disabled students as a whole. Rather, the intent here was that of an exploratory nature: to get a picture, a glimpse, into the daily school existence of a sample of students diagnosed with learning disabilities who share, through their own voices, their experiences on their journey into and through the special education system.

With this study, I hoped to add to a sparse body of literature that examines the educational careers of students with learning disabilities from their perspectives. The research endeavored here was intended to extend that begun by Adelman et al. (1983, 1986, 1990, and 1992) and undertaken by such other researchers as Davis and Ferguson (1992), Margolin (1982), Murphy (1992), and Phillips (1990). These researchers have begun to examine critically the process

of schooling through the eyes of the student stakeholders and, as a result, have come to question existing practices. It was my hope in this study to provide insights that will be of value to educators and policy makers as we continue to address the critical issue of how to best serve students with disabilities.

Chapter 4

PRESENTATION AND ANALYSIS OF THE DATA

I Have a L.D.: A Learning Disability -Or a Learning Difference
Written by Elaine, an 8th grader

When people ask me, "What is that?" it is hard to explain.
When people say, "Oh, you have that" it really makes me mad.
They will never understand what it is like...
to be tested and labeled and tested and labeled again.
They will never understand what it is like...
to be made fun of for something you can't help or change or
because you spell (what they think are easy words) wrong or
when you are in 8th grade you still write like a 2nd grader or
what it is like to try to read and get so confused or so embarrassed
you can't stand it.
They will never understand what it is like...
to cry for hours on end because you cannot figure out what is wrong with you or why God did this to you
but,
They will also never understand what it is like...
to read a whole paragraph right and have someone say, "Good job!"
because they do it every day and no one says "good job" to them because they do not have to struggle to read it correctly.
They will also never understand the feeling...
you get when you find a friend who supports you and tries to understand but does not pretend they do.
They will also never understand the feeling...
of a friend not thinking you are stupid but instead knowing how smart you are and helping you let it show and
just letting you vent about it and try to help you get through it because they will never have that.

I am not trying to sound stuck up or like this makes having a LD worth it.
But it helps you get through life without giving up all hope or
struggling alone the entire way.

They will never understand the feeling...
of having a friend that will not let you use it as an excuse but instead pushes you past it (but not too hard).
I have two friends like this and I would like to say thanks to them.
They are the best in the world.
Thank you Liz and Rachel.

Introduction

Elaine's poem, taken from the spring edition of Outlook, the newsletter published by the Learning Disabilities Association of Michigan, conveys many of the same emotions that are reflected in the tales told by the student participants of this study. The students were interviewed to solicit their stories regarding their educational experiences as students with learning disabilities. These students, like Elaine, spoke of having to cope with the shame and stigma of a special education label, the lack of acceptance and understanding by peers and adults, and the difficulty of accomplishing even the "easiest" educational task. In addition, their stories described their experiences mediating access to the programs and services provided under the Individuals with Disabilities Education Act, or IDEA. The students acknowledged the support and encouragement they received from significant others including parents, teachers, and, like Elaine, from friends who were there to understand, cheer them on, and, most importantly, accept them.

The nine students with learning disabilities who volunteered to participate in this study all attended Great Lakes High School. The sample included both male and female students who ranged from the ninth through the twelfth grade. The students had been in special education for differing amounts of time; some had received special education services from the beginning of their school careers while others were identified and found eligible as late as middle school. Information about these students follows.

Table 4.1

Student Participants

Name	Sex	Grade	Years in Spec. Ed
Tiffany	F	9	7
Heather	F	9	4
Ryan	M	9	7
Eric	M	10	9
Jim	M	11	10
Tracy	M	11	8
Tina	F	12	5
Devin	M	12	14
Amanda	F	12	8

Special education practices, as they exist today in schools, are defined by the Individuals with Disabilities Education Act, or IDEA. Like the Civil Rights Act, IDEA is born from an ideology that envisions a "free, appropriate, public education" (FAPE) for *all* students, regardless of any handicapping condition. IDEA provides eligible students with the special education programs and services necessary to enable them to receive such an education. Whether and to what degree special education students gain access to appropriate programs and services, as is their right, is largely dependent upon their, and their parents', ability to mediate between the procedural maze of rules and regulations and the district's implementation practices.

I began this study with a belief that student access to appropriate special education programs and services could best be explained through self-determination theory (Deci, 1980). My prior, professional experience had led me to believe that students who were denied opportunity to self-determine, that is, to give "voice" to their wants and needs, would be less likely to participate at their IEP meetings, or to self-advocate for the programs, services, and accommodations that were their right under IDEA. In addition to self-determination, data collected from the interviews with LD students and their parents revealed several other theories that appear to be equally critical to understanding these students' experiences.

To understand the influences that play upon how students exercise their voice, I collected interview data from nine high school students with learning disabilities and their parents regarding their educational careers as special education students. The responses of the students and their parents were organized around emergent themes that ran like common threads through their stories. In order best to present what was learned about student voice, the data unfold in this chapter in a narrative format that follows the students and their parents along their journey into special education.

For these nine students, the starting point of their journey into the special education system began with the process of referral, evaluation, and diagnosis. Along the way, the students encountered a variety of "roadblocks" that followed their diagnosis of a "learning disability." They needed to negotiate for programs and services in the least restrictive environment (LRE). We meet them again, as

they advocated for accommodations and the provision of appropriate educational programs and ancillary services under the principle of free, appropriate, public education (FAPE). Finally, we listen as they describe their participation at their individual educational planning team (IEPT) meeting. At each of these crossroads, we begin to gain a deeper understanding of the meaning of "voice" to these students.

What emerged from the students' stories are four themes that define their experiences: (1) Knowledge and understanding of the rights afforded to them by IDEA were critical to their ability to access appropriate programs and services; (2) How they came to understand and accept their LD label and the resulting stigma largely influenced their self-acceptance and willingness to access services; (3) The support provided by parents and teachers was a great source of strength and comfort to the students; and (4) The students' desire and ability to self-determine, to have "voice" in developing their individual educational plans, were affected by the three preceding variables.

There are several theories that help to clarify the students' experiences. Labeling theory (Mehan, et al., 1986; Langer, 1983; McDermott, 1993) helps us to understand the how their special education labels affected the students' sense of identity. The students' desire to self-determine, to have voice in developing their individual educational plan and in advocating for their rights can best be interpreted through self-determination theory (Deci, 1980). The students' and parents' knowledge and understanding of IDEA and the students' disability – or

lack thereof – impacted each of these other influences and was interwoven throughout the students' stories.

Each theoretical perspective can be thought of as a separate lens within a kaleidoscope. Certain of these theoretical lenses serve to better explain the various experiences particular to each student. Twisting and turning the kaleidoscope produces many unique and varying images. So it is that similar theories serve to variously illuminate the experiences of the individual students as they mediated access to programs and services. Students' stories are presented as vignettes within each of the various principles of IDEA so as to walk the reader through the process in a way that mirrors the experiences of the students and their parents during their journey. Citations are presented to support assertions regarding the findings. The following chart indicates where the relationships are strongest between the emergent themes and the IDEA principles named above.

Table 4.2

Themes Related to IDEA Principles

Principles: **Themes:**	**Referral, Evaluation & Diagnosis: Entering the Program**	**LRE: Defining the Place**	**FAPE: Advocating for Accommo-dations**	**IEPT Meeting: Opportunity for Student Voice**
Knowledge & Understanding of their Rights	X	X	X	X
Labeling	X	X		X
Self – Determination	X	X		X
Social Capital	X	X	X	X

The Referral, Evaluation and Diagnosis

Entering the Program: "to be tested and labeled and tested and labeled again" – The journey begins with a referral

There's a beginning to every journey and, for these nine students, the journey began when someone, typically their general education teacher or their parent, recognized their struggles and initiated a referral for a special education evaluation. All of these students had academic difficulties that were reading-related. Like our poet, Elaine, they could recall times when they would "try to read and get so confused or so embarrassed you can't stand it." Jim, Amanda, and Tracy shared their recollections of their earliest struggles. Jim recounted

how, in the first grade, he had difficulty learning how to read that, he realized later on, was most likely connected to problems with his hearing:

> I lost my hearing. I had to have tubes in when I was six. So I missed my first couple of years – I couldn't hardly hear at all. And, there's a theory that that's why I got behind. And one of the reasons why I got put in LD classrooms. And I never caught up. They'd give me an assignment, and it would be hard for me to hear them. After, I got my tubes in. I got my tubes in the first grade- so I missed everything in kindergarten and part of first grade, when you're learning how to read and everything. So, I didn't understand how to read for a while, until second grade or so.

Amanda also recalled her difficulties learning in the general education classroom. She reflected,

> I just remember that I was slow at reading. It's just that sometimes I say different words from what they really are. Or I just can't say them. Reading out loud- I don't do too well. I don't like to.

Tracy remembered that he was in the fifth grade before an adult first noticed his struggles with reading:

> I think that pretty much started about fifth grade. Cause I remember that one time I needed help with something. And I read something, and the lady told me what it was, asked me what it was talking about, and I said, 'I don't know. I don't remember.' And, she's like, "What? You don't remember!" And I didn't realize it had anything to do with my disability.

Many of the students relied on their parents to secure the academic support they needed. Seeking a referral for special education begins a long process, characterized by mountains of paperwork and numerous meetings, that can be particularly daunting. Many of the parents reported how they were thwarted in their attempts to have their child evaluated. Lacking an understanding of the process and their rights, they faced several roadblocks: disagreement by the school authorities that an evaluation was necessary; an unsolicited

"diagnosis," without an evaluation, by the child's teacher that he or she had another "condition" (such as ADD/ADHD); or a request to delay testing until the child was older or had reached a certain grade.

Ironically, in what may seem like a contradiction, having other family members who had a disability provided parents with a knowledge base that served them as a resource in their pursuit of special education services for their child. For these parents, this prior experience provided them with a comfort level, a familiarity with the field, the professional jargon, and the process. The stories told by Brian's, Devin's and Tina's mothers best represent the ways in which this resource helped them during their journey to access special education programs and services for their children.

Brian's mother, who had other family members who had attention deficit disorder (ADD), remembered that she had to persist to get the district to agree to evaluate Brian. She recounted, "I think I tried to get him evaluated in first grade, and they said no, he had to be two years behind." Devin's mother became involved with accessing special education services for Devin when he was just a baby, coping with the challenges of cerebral palsy. She recalled a long battle with the school when it came to having Devin evaluated for a learning disability:

> His October conference in first grade, they told me that they were going to hold him back. And basically, they didn't do anything with him for the rest of the year. I fought for the rest of the year to get testing for him, because I didn't think it was immaturity- it was a learning disability. From then on, I really had to stay on top of it...He was getting his occupational and physical and speech therapy, and then they added for the learning disability. But it was a fight to get it.

Tina's mother, whose two other daughters also had learning disabilities, recollected that her attempts to get testing for Tina were thwarted by the teachers' belief that Tina and her sisters had ADD: "They tried to tell me at first that they had ADD, and we fought that issue for a year, because I wouldn't let them put them on medication."

The fact that the students were finally evaluated attests to the parents' tenacity in acting as advocates for their children. For these children, such acts of parental support served as a critical resource, the driving force behind their access to programs or services that might otherwise have been denied. In addition to parents, there were occasions when a teacher also served in the role of advocate or "gatekeeper," assisting the parent, such as Eric's mom, in obtaining an evaluation which later led to needed services:

> We couldn't get him into any (special services) here because they don't get to anybody until they're in first or second grade. So, finally, by the time he got to third grade with Mrs. Manner, who is now retired, she got him into the special ed program. She told me, "This kid isn't making it. They're just pushing him through!"

Parents, especially those with prior knowledge regarding disabilities, and knowledgeable teachers could be powerful influences in the lives of students who might otherwise fall through the cracks of the system. Having social capital in the form of strong parent and teacher support served to help students who were neither, themselves, informed nor empowered, to access programs or services that might otherwise have been denied them.

The evaluation and diagnosis: "Oh, you have that..."

The evaluation can be viewed as the "signal" to the students that their journey into special education was beginning. None of the students recall having any knowledge that they had even been referred for an evaluation, and they only became aware that "something" was going on when the school psychologist pulled them from class for testing. The students could not remember having the process explained to them, much less being asked how they felt or what they thought about the possibility of receiving special education services.

The students who were referred during their early years in school (first, second, or third grade) had difficulty remembering what the evaluation was actually like. If they were recalled at all, details of the testing that took place were often hazy and confusing. These students must have felt that they were on a journey with no roadmap - and an uncertain destination. Their confusion and lack of knowledge about where they were headed, and their lack of an opportunity to self-determine, to have voice in the process and to be involved in the decision-making about their education, continued throughout the testing and diagnostic stages.

Jim and Brian described the confusion they encountered at this juncture in their journey. Jim remembered, "It was like a game. They just asked you questions, like trivia questions and puzzles. It was okay. It didn't really seem like anything special. I didn't really know what was going on." Brian provided a similar account: "There were some puzzles that you had to do- that's all I really

remember. They were times puzzles, putting them together with pictures. I wasn't really embarrassed, I was kind of nervous."

Several students who were tested later in their school careers still lacked a clear understanding of the purpose behind the evaluation, which led to a general disinterest and a sense of disengagement. Amanda recollected, "I got tested and that was about it." Heather recalled struggling in math and failing to do her homework as the reason behind her referral for testing: "So, I didn't do any of my work and they were like, well, we're going to test you. So they tested me." Tina was evaluated in the sixth grade and reflected on the process: "My mom asked about it, and then they did it, and we got it back and they said, 'Oh!'"

This lack of clarity about the process was pervasive; as a result, students lacked the ability and opportunity to self-determine, to have any say in whether they would be evaluated and labeled. While parents routinely make many decisions for their child with regard to medical procedures and treatments, music lessons, religious affiliations and training, the decision whether or not to enter special education has other, far-reaching implications of which these students were unaware. Having a special education label means that one becomes, in the eyes of the law, an individual with a disability, part of a "class" of handicapped individuals. According to labeling theory (Mehan et al., 1986; Langer, 1983; McDermott, 1993), the label affects not only how one is viewed by others, but also how one comes to view oneself and create a self-identity. Without any say in the matter, students were identified as "handicapped" and became members of a

class of individuals who had specific rights and privileges, but who also had to endure stigma and alienation.

For each of the students in this study, evaluation resulted in a diagnosis of a learning disability. The students' confusion continued with their diagnoses; none of the students recalled having their learning disability explained to them at the time. Labeling theory helps us to understand how some students were able to come to terms with their label, and eventually "forget about it," how some continued to view their label as a painful fact of their identity, and how others continued to exist in a state of denial.

What, how, and when the students came to understand the meaning of this term varied widely; for some, parents played the main role in explaining and defining it, for others, it was their teacher, either at the individual educational planning team meeting or in a particular class. Having a knowledgeable parent or teacher to interpret and explain the "system" helped students come to understand and accept their disability. The students shared stories that exemplify their recognition of how important having this type of resource was to their self-acceptance and their motivation to access services. Tiffany acknowledged:

> I didn't know what they meant by 'learning disability' until I had this study skills class. We learned about our disabilities. I always knew I had a learning disability – I didn't understand things. Then I found out what that meant, and I thought, "I can get over this." When you learn about something and understand it, it helps you think you can conquer it.
>
> There wasn't any stigma until middle school. I would get teased sometimes, called 'retard'. It didn't bother me- I just didn't pay attention and ignored it. I liked getting the extra help.

Tiffany's mother played a supportive role in explaining the purpose of Tiffany's special education placement to her so that she could accept it:

> I explained it to her as, 'You'll have teachers who will help you understand, who will explain it to you, more of a one on one. She'll be there to answer the questions for you and help you with it if you need the help.' So she was okay with it.

Jim, also, was unaware of the meaning or implications of having a learning disability, or that he would be receiving special education help. Jim's teachers were the ones he relied on for the explanations and support he needed to accept his disability:

> I didn't really know what was going on. I didn't even realize I was in special ed until, like, third grade or so. I just went to a different classroom. I didn't realize it was special ed. I don't think they ever really explained it (meaning of LD) until I took Communication for Empowerment last year with Mrs. Woodard. She explained it in a lot of detail- laws and everything. I learned a lot about it. It was pretty interesting. I think I kind of figured it out before that, but I don't think anybody ever sat down and explained it with me and told me everything about it. I kind of knew I had a learning disability and that I had special classes. But I didn't know about all the accommodations I could have.
>
> I don't really see much that's different with me from any other people...I need to take more time. I have to reread stuff and do more rough drafts to get all my thoughts expressed and recover everything from the books and the packets. It's pretty common to have a learning disability.

Jim's mother remembered the difficulty they had diagnosing and labeling Jim's disability. She was able to understand and explain what it meant because she had experienced it herself: "It wasn't like they said it was dyslexia or this or that. They even had a hard time labeling that at the time. I did pretty much understand it just because it was basically the same thing I went through type of thing."

Brian's account, like Jim's, reflected a similar sense of confusion that was later clarified by his teacher's explanation. He felt strongly that students needed to understand what having a "learning disability" meant in order to be able to accept it:

> I wasn't really sure what to think about it, because I didn't know what was going to happen or what was going to go on. When we were switched to a different teacher, we moved around for reading and stuff, we would just go to her instead. That was probably like the fifth grade since I knew that (I had a learning disability). I didn't really "get it" until I was older. I felt like I understood why I didn't "get it"; I cannot do it and it takes me more time to learn and to read the same words they can. It takes me a lot longer than it takes them. I can still do it, it just takes more time. I have more of a problem with writing words and spelling.
>
> Now it's better to know that you have a disability, but when you are younger, you just think that it's your fault. She (the teacher) explained it so that it didn't make it feel like it was your fault, or that you had any control over it. And she was trying to help. It wasn't like that you were retarded or anything like that. She got really mad when people said that, and she explained the difference between those two. They need to tell them that's why they're being tested, because they have a problem, and to see if they can get them more help.

In addition to having his teacher as a source of support, Brian was fortunate to have a strong relationship with his mother, who relied on her own personal and family struggles with dyslexia to help her make sense of Brian's learning disability. His mother recounted how she explained his disability to him:

> I'm trying to think how I did explain it to him. Probably along the context that he did not learn things the same way as other children did. I'm somewhat dyslexic. I have a lot less of a problem than either my son or my brother did. So, I could talk. He and I have always been able to talk. And I could talk to him a little bit about what was going on. Well, he knew he saw letters backwards, for instance, upside down and backwards – he's a true dyslexic. I know I talked about it with him.

Devin began his journey into special education long before the others when he participated in a preprimary program. While he was always aware of the

limitations imposed by his cerebral palsy, he relied on his teacher to help him become aware of his learning differences through a class designed for that purpose:

> Ever since kindergarten, I was in special ed. Really, as I got older, I realized how difficult school was for me. Probably about tenth grade, I finally realized what kind of learning style I had and how I learned and through what strategies are best for me. Second semester, I took a class called Communication for Empowerment with Mrs. Woodard. And we had gone through certain packets of overheads to figure out what our learning style was and how we learned. And so, it was more through a class, but yet it really helped me because then I knew what ways I needed to go about getting my work done, and what ways would make it effective for me to learn the best.

Devin's mother and his teachers had been extremely supportive, accepting, and encouraging. With their support, Devin was able to come to terms with his label and to view it as a way to get the help he needed in school:

> I mean, yeah, it may be a label, but to a certain extent, outside of school it doesn't affect me. I just do what I want to do and act the way I want to act.

Self-determination theory also helps us to understand how Heather experienced the evaluation and labeling process. Her account reflects her anger at being "sent on a journey without a map." Denied voice and lacking an understanding of her learning disability, Heather experienced a sense of denial:

> I was never really told about anything. It was like, "You're going in this class right now." And that's it. That's all I heard. He just gave me the test, talked to me about my family and stuff to make me feel comfortable, and then, about a week later, I was placed into special ed classes. They said they didn't know when I would be able to get out, and if I would ever get out. They weren't sure. It kind of made me mad when they did it. I thought, "There's nothing wrong with me."

Heather relied on her mother to make sense of what was going on. Heather's mother recalled how she attempted to comfort her daughter by explaining why she was going to receive special education support:

> I told her that she seemed to be struggling. We discussed it a little bit. I told her, "Maybe you need more help, you know?" And I knew it was a full range of help. It could be that she needed special services. So, that's what we talked about. And I wanted her to be successful in her school career, and so I felt that maybe we should go through with this. And she felt comfortable with that because she knew she was struggling.

Heather told a story that demonstrates how crucial it is for those who serve as a source of support and advocacy for students to have the appropriate knowledge and information. *Mis*information from a trusted individual could have very devastating effects on the students. The following vignette, from conversations with Heather and her mother, serves to illustrate this point. In Heather's story, a caring but misguided teacher explained her "SLD" label to her as meaning "severe" learning disability rather than the correct definition of "specific" learning disability. This one piece of misinformation was the source of a great deal of anger and denial for Heather. An outspoken freshman, Heather described her reaction and her feelings of "wanting to give up":

> The first time I learned about my learning disability was with Mrs. Bailey. She brought us our IEPs and told us our disabilities. And I was pretty upset with it. I was very furious, because I felt that that wasn't me. I'm more advanced than the disability they say I have. And it really made me upset, because I don't think I have a severe learning disability. I think if I really, truly put my mind to it, I could do it. It was hard for me to take, but in another way, I knew I had to have it.
>
> But, just how they label kids- I think it's wrong. Because "severe learning disability" makes you want to give up. That's why I felt like giving up. I thought, "a severe learning disability – you can't do nothing!" You know, you can't learn anything. Which I know I can. And severe means, you know, it pretty much means you're bad off. And I don't feel I was bad off.

> And you know, I think that there are issues with how they're naming kids wrong. I think that not all kids are severely learning disability. I wasn't severe when I was younger. I just was- I think that I had a learning disability- that's it. You know, you say "severely learning disabled" and, before they start getting mad about it, I think you should start explaining how come that is. Because I just knew that severely learning disability – that's what your title is.
>
> And what is a severe learning disability? You didn't go into that information- how you came to that assumption! How can you tell me what that means? And I feel that they're just putting me down! It wasn't explained how you guys came up with that. It made me mad! Kids are sitting there saying, "How come you're labeling me this way? You're not explaining it." I think it's very important, even to young kids. I think it truly is important to a child to learn what their disability is, but also how they got that disability and why they're labeled. It hurts, you know, to find out why you got labeled that way. But, you know, then you start understanding yourself and start improving.

Heather's mother remembered her attempts to deal with her daughter's anger over the explanation of her special education label. Her assurances and calm acceptance helped Heather cope:

> I think she felt that she would never get out of special ed. To be like all the rest of the other kids. Because of those labels that were already put on her. Once I told her, "You're getting the extra help. You're special ed because you need extra help in order to accomplish the same task, you know. And that means you have to work harder." Once I told her that, she started improving. Applying herself. Shutting everything out as far as labels and stuff and sticking up for herself. It gave her a tool to say, "I'm no different than you are. I just have to work harder than you."

Amanda's comments throughout the interview indicated that she had never been able to fully accept her disability. She, too, had never had voice in the process and might have chosen not to take this journey. Her mother admitted that she never really did explain her daughter's learning disability to her but, instead, took what she described as a "matter-of-fact" approach toward the opportunity for Amanda to receive extra help. As a result, she believed that, for

several years, Amanda remained unaware of the fact that she had been labeled learning disabled and was in special education:

> But, as far as me going into it, I just said, "This is a different class and go and do what you have to do." To tell the truth, I don't think she realized she WAS in special ed until eighth grade. She admitted she struggled in a couple of classes at that time and agreed to have some extra help.

Amanda may have agreed to the help, but she resisted being classified as "handicapped" and believed that she could not be defined by a label. She stated her conviction with great clarity:

> I just don't like the label they put on. They make you think of handicapped people and I think that's not right. They're regular people who just have a disability with reading or writing. I just don't like a label on me. I'm not a label kind of person.

Tracy's mother remembered how he struggled with school in general, and discussed his understanding and acceptance of his disability:

> I just think, gradually, he kind of knew he was different. I'm sure it probably happened right away in school, knowing he couldn't keep up and couldn't keep focused and that type of thing. So, I think right away he knew, but it probably didn't matter at that point until he started growing older. He never really showed that it bothered him a lot, at home, but I'm sure that it did. It's different for kids like him who can't focus like other kids can.

Tracy accepted the help he received, but confessed that he was confused with why he had to go to a different place, "down there," to get extra help. His comments reflect his sense of uncertainty:

> I remember going to resource room just because I had ADD. I didn't really know what that meant at the time at all. I got extra help for the math and all that stuff. I didn't really understand why I had to go down there- cause I had ADD, and I didn't know what that meant. I just accepted it and all because I got extra help with math and reading.

Like Tracy, Eric was also uncertain about the meaning and extent of his disability, but his mother stated that, regardless of the evaluation process and ensuing label, Eric had already realized he had a problem:

> He was already suffering. Even when you're in second grade, you know when you're not keeping up with the kid next to you. You know, so he knew it was so he could get more reading help. Which made him happier. Cause the last thing he wants to do is to look stupid. I mean, that's the way you lose your kids. You start your attitude way down there in those grades, and they just get bigger by the time they get up here in the high school grades.

Eric's concern with his label revolved around its possible affect on his future goals. He believed that being labeled as learning disabled might be a stigma and lessen his chances of getting into college:

> My biggest concern is later on – kind of when I choose a college. I think that other kids, who don't have a disability, and if we have the same requirements and get the same grades, I think that because I am a resource student, and they look back and see "Resource English", or something like that, they'd probably pick them over me. That's what I'm thinking.

Understanding and acceptance of their diagnosis and label was often a product of caring and supportive relationships with parents and teachers. Many of the students in this study had such adults who took the time to explain it to them in terms they could understand. The matter-of-fact approach by these adults, coupled with the message that this was "just another way" to get the help they needed, supported the students in coming to grips with the fact that they were now "in special ed." Once they understood their learning disability, many students were able to overcome their abhorrence for their label and to see it as the "price they had to pay" for special education services.

Least Restrictive Environment

Defining the Place: "... it helps you get through life"

Once the students acquired their new, "special education" identity, they were confronted by many ongoing challenges as they attempted to mediate for special education programs and services to address their academic needs. The law provides for special education programs and services to be delivered in the least restrictive environment. This is always the general education classroom setting, unless it can be determined that the student cannot benefit from such an education, even with supplementary aids and services. Many students, including the participants in this study, require accommodations or instruction that can best be provided in the smaller, more intimate special education resource classroom. The students in this study told stories of journeys that were arduous and often characterized by uphill battles with stigma and alienation that resulted from having to access services set in a different "place" from their general education peers. What we learn from listening to their stories should not be surprising, that "place" results in stigma and affects student decisions with regard to using their voice.

While parent and teacher acceptance, advocacy, and encouragement enabled many of the students to overcome the negative effects so often described by labeling theory, placement in special education classes-- a different environment -- remained an issue for students with regard to peer acceptance and relationships. Students had strong feelings about how and where they were

provided with special education services and the affect this had on their peer relationships and self-esteem.

Although Becker (1963) discusses "deviants" and "outsiders" in terms of those who stray from following group norms, these concepts also help to explain the students' stories. While the special education label, itself, may not have been a direct source of stigma for some of the students, it implied membership in a group (special education students) outside the norm (regular education students), and made students feel like they didn't belong – that they were "outsiders." Nearly all of the students reported feeling conspicuous and "different" among their peers when they needed to access special education services. They described situations where they were embarrassed by the fact that they were in "special classes" with "special teachers." Several students reported that they did not know how to make sense of their special education programs to their "regular education" peers. The following citations best illustrate the students' experiences. Jim acknowledged,

> It was kind of weird, because they took you off to a special ed class and they don't really tell anyone else what it's about, so everybody questions you when you get back. "Where did you go?" type of thing. Plus, I saw speech counselors and stuff, so it was always different. Like, I came back in the middle of stuff and kind of got lost.

He thought back to teasing and harassment that took place when he was in middle school and needed to attend a special education class located outside, in a portable classroom:

> In middle school, there was an outside classroom- like a portable that you would have some of your classes in, and kids kind of knew that they were like the "retard" classes, or whatever they want to call them. So, you got kind of picked on more about that, because it's not just another classroom

in the building. It's the "special ed classes" out there. So you get picked on more about that.

Eric was very sensitive to the fact that he stood out as different in front of his peers whenever it came time to go to his "other class":

I felt like I was dumb or something. When the teachers walked down, they picked you up in front of other people and other kids kind of knew it was the resource teacher, so I kind of felt like you were an outsider kind of.

Tracy discussed his earlier school years, when he was often picked on by his classmates. He saw this as a result of his own, inappropriate behavior at the time, as well as the fact that he was in special education:

I was made fun of a lot, so I pretty much wanted to be out of there (regular ed classroom) a lot of the time. Truthfully, I was a dork. I mean, looking back now, I don't know. I was just a dork. I just did stupid stuff. Now, we just mess around mostly. I have a lot more friends than I did back then. It's not really a big deal anymore. People used to make fun of me because I had to take pills all the time.

Devin's mother believed that Devin had never fit in with his peers, and related several cruel incidents that took place during his middle school years:

When he did try to tell a joke, it wouldn't come off as a joke, and it would come off more silly or stupid than anything, and then the kids would make fun of him. So he'd try, but it didn't come out the same. And I think he just kind of started withdrawing because of the cruelty and stuff. He'd fall asleep (due to his seizure medication). There was an incident where kids would pick up his head and let it drop and slam on the table. And it happened a few times before somebody finally put a stop to it.

Middle school was the worst. They're cruel in middle school. That's when he got the most teasing and deliberately left out. And he was the most sensitive then. At middle school, it was hard. In high school, freshman year was hard, but each year got better. And he really enjoyed his junior and senior years.

And as they got older, they were more accepted. Except by then, if the kids aren't outgoing enough to push their way in, the kids don't open the door. You know nobody – soccer games, when the team would be leaving they're talking about "Let's go get a bite to eat. Let's go to Burger King,

> McDonalds." Nobody ever asked Devin, "Hey, Devin, you want to come?" Four years of soccer and you know he was on the team and everybody talked to him and he was part of the team. But there was never any trying to draw him in and be his friend.

For Heather, feeling different from her peers in school resulted in a lack of self-esteem and a decline in her motivation. The label had a major influence on how she came to define herself as a member of a group of "outsiders." Heather's mother related an incident that occurred during her middle school years:

> Middle school, towards the end of it, was becoming a struggle. Probably in about seventh grade, two years ago. Peer pressure. Being labeled "dumb," and stuff like that. In junior high, they seem to start developing their own little groups. So, the group she was in was with students she had classes with, which were comparable skills that she had and, so as a group, they had these labels. And individually, they would have those labels, because they were part of that group. Because that group sat together from having the same classes. I mean, that's just the way it is.
>
> She had trouble with that stigma, because she knew she wasn't dumb, but she was beginning to believe it, because they're shunned more than anybody else. It came to the point that she was actually displaying that same kind of behavior at home, kind of like an "I don't care" attitude. But not really meaning it. You knew there was something bothering her. I ended up asking her to do something at home, and the words out of her mouth- which she must have had a bad day at school, a lot of teasing or something- first words out of her mouth were, "Well, I can't do that, Mom. Don't you know, I'm 'special ed'."

Tracy believed that learning about other peoples' disabilities would lead to seeing past their differences and labels, increasing peer acceptance and reducing teasing:

> I think it's also important to know what other people's learning disabilities are, so you know why they're having trouble instead of just saying, "Oh, they're different. I'm going to make fun of them." This one kid in my class, he has a hard time writing. And eventually, I realized that. I think he has dysgraphia - every time he would write, it would just look horrible. And I would make fun of him cause of it. Then I learned of dysgraphia and I realized that he can't help it, and I stopped making fun of him because of

> it. Because what if I had it? Would I like to be made fun of like that all the time?

Devin's comments are reminiscent of those of Elaine, our poet, who described crying "for hours on end because you cannot figure out what is wrong with you." Devin advocated recognizing that people have different learning styles instead of interpreting a special education label to automatically mean something's "wrong":

> I guess it's the whole thing as far as your friends and peers and classmates learning, not what's *wrong* with you, but how you learn, getting to know how you learn and so they won't think, "Oh, well, they're going to that room to get this help or that help."

Amanda appeared the most uncomfortable during the interview. Of all the students, she was the least open about her disability and became agitated as we discussed the topics of label and stigma:

> No. I don't say it. I don't tell anyone that I have it. None of my friends really know I have a learning disability. I don't really go around, "Hey!" But they might know if I read out loud in front of them, or something. But, usually, I skim it down and know what's going on.

Amanda was extremely self-conscious about her special education label and the fact that she received special education support. She shared the pain expressed in the poem by Elaine about being "made fun of for something you can't help or change." Amanda was very hesitant to access special services if it meant that she would be "detected" by her peers, and thought other special education students shared her sense of embarrassment:

> It was a little embarrassing sometimes when people knew that you were going to the special ed classroom, or something. Cause they know Mr. Strongman, and if they looked in the yearbook, it will say "Special Ed Teacher," so if you're going into his room, then they obviously know. I mean, I think everyone would know that- if you're going to see that teacher

> or leaving the classroom to have a quiet time. I mean, I know in my history class when one kid would walk out with a test, I would know where he was going. And I would just sit there cause, sometimes, I wouldn't need that. I mean, you know people are leaving to have quiet time, to go see Mr. Williams. I think that's probably why they don't take the extra time.

Her mother confirmed the fact that, because of her fear of being "found out," Amanda did not fully access the accommodations available to her through her IEP. As a result, her grades were often poor. Her mother regrettably acknowledged,

> ...whether that means sitting in the hallway for tests, or having it verbally read...she was offered that (in high school) but she did not take advantage of it every time that she was offered it. She could have done better.

Many of the other students also attempted, at times, to keep their special education eligibility hidden from their friends. Many chose not to disclose their disability – rather, they traveled in secret. This sense of shame and secrecy varied by degree among the students. Brian related,

> They don't really even know. I mean, they never – if you're made fun of when you're younger, it could be (embarrassing), but I wasn't. I just really --I don't even act-- I don't even tell people anymore. I just go on with doing my stuff and ignoring what people think. I let them think what they want. Nobody knows it's a resource room. There's not like a giant sign on the door that says that, so they just think that you are going to one of your classes.

Devin, who was eventually able to accept his special education label, admitted keeping the fact that he had a learning disability to himself until he felt comfortable;

> It depends on how close I am to them. I mean, I won't come out and tell them right away. But, as I get closer to them, I'll tell them. As I get to know them, I open up to them more.

Students found various ways to cope with stigma and teasing. While some students decided not to disclose their disability to their regular education peers, others chose as their friends other students with disabilities, with the belief that they had more in common and felt more comfortable and accepted. In this way, students were able to create a group where they were no longer the outsider. Jim admitted that choosing friends from among his own peer group in special education classes led to a greater sense of acceptance:

> A lot of people don't know about it (my special ed label). And the people who do know about it, I'm in classes with them and they're classes for LD students, so everyone else has the same problems that I do. Now you make the transition from class to class every hour, so people from your last hour don't know what hour you're going to next. So a lot of people don't know about it. I've been picked on about it before, but most of my friends are kids in the learning disability program as well, so they kind of understand it and they don't really pick on anybody about it, because they have one.

At some point on her journey, Tina had been able to overcome the sense of stigma that resulted from her special education status. She now looked at special education as "a way to get me through school." Like Elaine, the author of the poem who described the importance of having a friend "who supports you and tries to understand but does not pretend they do," Tina saw supportive friends as being critical to her self-acceptance. She maintained, "I think it shouldn't matter. If your friends are supportive, you don't care. But if your friends are, 'Why are you doing that?'- you can't talk to your friends. Then it matters."

Tina's younger sister was also in special education, and hated it –rejecting any affiliation with that deviant group. Tina reflected on her sister's sense of embarrassment, attributing it to a difference in the way the two girls approached

the situation. Like Jim, Tina also chose her friends from among her special education peers:

> With my sister, she was embarrassed cause she had special ed. With me, it didn't really bother me. I didn't care. She was upset because people would call her stupid or dumb, because she went to special classes. And with me, it was kind of like, okay, well, I'm just going to get help. So, I just blew them off. They're just kids – we won't see them again. Hers (friends) were all just general ed. A lot of my friends are special ed. When I first started, in sixth grade, when I got it (the label), my friends weren't. But, they understood it was a learning disability. It's not like I have this disease or anything. And a lot of my friends are more mature than her friends. When I grew and kept on going, I met new friends and they actually became my best friends. They were actually in the special ed classes, and that's how we met. And I found that I had more in common with them. She is not that way. She's "I don't want to be this way. I don't want to do this (go to special ed classes). I want to have *normal* friends." But, you know, everybody has one problem with something, so...

Tina attributed the fact that she had grown more comfortable with being in special education to the sensitivity that was demonstrated by her special education teachers:

> They [teachers] kept all my stuff pretty much confidential, so kids didn't know. They wouldn't take me out in the middle of class. They would meet with me after school and talk to me then. It made me feel better. I don't know if they did that with her [my sister]. Maybe that's why she was kind of like that. It made me feel a lot better.

Tina's mother remembered how Tina began to accept the fact that she had to go to another "place" to access special education support:

> At first she was embarrassed she had to go to the [special education] classes. That was something. "Well, the other kids don't know." Well, of course they do! She was embarrassed at first, and then she finally got to the point where, "Well, this is helping me. I don't care."

She discussed how her other daughter was never able to overcome the stigma and the sense of being different from her peers that she felt whenever she had to leave the general education classroom to get help. She had reached the point

where she was refusing to attend school and often spoke of dropping out. Her lack of self-acceptance seemed to have paralyzed her ability to accept help, to speak out and self-advocate. Tina's sister was an example of someone whose lack of belonging, whose sense that she was "deviant"- an "outsider"- so consumed her identity that she "shut down."

A few of the students were not ashamed of being in special education and did not seem to be troubled by any ongoing stigma associated with having a learning disability. If they had faced teasing, they had handled it successfully. Tiffany felt as Tina did; she found the special education help she received to be very necessary and valuable to her. She stated outright, "I liked being in special ed. I liked the teachers and the extra help they gave me." While special education was not stigmatizing for Tiffany or Tina, other students acknowledged some stigma from accessing the special education class, but were willing to overlook it because of the extra help their special education eligibility brought them. These students and their parents saw it as a "trade-off."

Eric's mother agreed that being in special education was somewhat of a stigma for him, but it was the "price they had to pay" in order for him to receive the extra help:

> Yeah, I do (think the label of LD has been a stigma for Eric with his peers). But on the other hand, you don't get everything in life that you want, anyway. It would have been worse not to and leave him in regular classes. Everything's a trade-off. I've approached it like that.

Eric agreed, stating that if he were given the choice, he would choose to remain in special education; "I think I would stay. If I could have my way, if I could say. 'Yes, I want to be in it' or 'No, I don't', I think I'd say 'yes' because it actually

does help me a lot." Eric's mother believed that his involvement in many other outside activities, where he was not seen as an "outsider" but as a legitimate member of the group, helped him to accept his label and profit from his special education classes. She described how this was not the case for Eric's younger brother, Rick, who, like Tina's sister, was unable to cope with the stigma attached to "place":

> My ninth grader, Rick, is real conscious about a pull-out class. He's not a good one for pull-out, cause he's real conscious. I don't think Eric cares about getting on someone else's case because he does so much other activities. I'm talking like church and sports and things like that.

Devin's mother related how he had been able to deal with peer issues because he realized that the special education support he was receiving was critical to his success in school. She reported overhearing a conversation between Devin and his stepsister where he described his realization that, despite what others thought, he needed to have voice:

> Devin sat down and told her, "You know, when I was a freshman, it was really hard. I felt really stupid and I didn't fit in." And he said, "I figured out that if I want to make it in the world, I need to speak up and not be embarrassed about it."
>
> He just got to the point where- "This is what I need and to heck with everybody else. If you don't like it, then-" He wasn't embarrassed to have to ask to take his test somewhere else or to ask for extra time, where his freshman year, based on his account to his stepsister, he was embarrassed by everything, that he had to be in special classes and taught differently. And he just quit worrying about what everybody else was saying. It just was more, "Accept me for who I am, and if you don't, then I'm going to be fine, too."

Such disparities among the students' responses mirror the tensions in the field of special education between the different schools of thought related to labeling of students and delivery of programs and services. Some of the

statements made by students both corroborated *and* contradicted arguments for and against inclusion. That is, while students acknowledged a sense of stigma and non-acceptance among peers, while some felt so isolated as to consider themselves as "deviants" or "outsiders," *all* of the students in the study gave voice to the fact that, if they were given the choice to self-determine, they would tolerate their special education status in order to receive additional help and support. The students may have preferred to remain in the general education environment – the argument put forth by those in the field who promote full inclusion – but they also acknowledged that they benefited from the individual attention and small group instruction they received in the homogenous, special education classroom setting. Students' stories were testimony to the difficult, sometimes agonizing decisions they were forced to make. Their responses reflected many of the complex considerations put forth by practitioners and researchers in the field of special education with regard to the least restrictive environment.

Free, Appropriate, Public Education

Advocating for Accommodations

As they travel on their educational journey, students may encounter unexpected challenges at every turn along the road. Schedule changes, new teachers, higher curricular standards, teachers who adhere to the ways of the "old school" – all of these may conspire to complicate and obstruct the students' journey. Under IDEA, students with disabilities are guaranteed a free, appropriate, public education (FAPE). Our nine students and their parents shared

many stories about the appropriateness of their educational program in addressing their individual needs. They described how, traveling without a roadmap -- a working knowledge of the law -- they ran into roadblocks that made it difficult at times to receive the accommodations and services identified in their individualized education plan (IEP).

Coping with the process of referral, evaluation, diagnosis and labeling, and the resulting stigma and sense of being different were not the only challenges faced by the students and their parents. According to many of the students' accounts, accessing appropriate programs and services was often difficult as well. When they did succeed in receiving services, some students and their parents felt that the support provided them was, at times, either not adequate to meet their needs or not challenging enough, even to the point of holding them back. At many of the crossroads in their journey, students were required to give voice to their wants and needs. They often relied on social capital, parent and teacher support, to help mediate access to appropriate services.

Several of the students and their parents felt that the special education services they received had always been appropriate and had met their needs for support. Tiffany's mother felt that her special education program was very helpful: "I truly think that the resource room has been very helpful. Now that she is out of resource and she'll be in co-taught, I think she feels comfortable with that." Brian also believed that his special education classes provided him with the appropriate support and level of work:

> It was a lot easier after I started taking that [resource class], cause they weren't trying to force you into reading something that was way, a lot higher, than where you are supposed to be at. Stuff like that...I was happy I didn't have to be in that [general education] class any more, doing the other work that I didn't get. I think I would have [liked to have] had more resource room than what I got. Because it was a big help. when you don't understand what is going on in the classes you have, it's a big help to go to classes where they are actually teaching you.

Despite her loathing of her special education label, Amanda admitted that she benefited from the extra help and accommodations she received from her special education teachers who supported her in her general education classes. She preferred such co-taught classes where two teachers, a general education teacher and a special education teacher, were able to help everyone, and where stigma was less of an issue:

> I think we get more chances. More time to do tests. And get pulled out of class to go to a quiet area. And we have more people caring about us, I think, than regular teachers. Cause Mr. Williams sees me on a daily basis. And he also sees me during class if I need help, or after school or before school. He makes a little more time for us than regular teachers. Mr. Williams is a good guy, you know what I mean? If I asked him for help, he'd do it that way. Or, if I didn't understand something, he'll stop and do it again or do it again till I get it.
>
> Co-taught classes are good, cause not everyone in that class needs help, but it's also a good thing to have two teachers in there. You can get more answers than with just one person. I've only taken a couple of them, but that was better, cause you have two more people to answer questions, and if someone can't answer them, someone else might be able, or reword it. Co-teaching- I liked that a lot in high school. I didn't have it freshman year, but I had it in science class. Ms. Briar – she'd go around and help everyone, not just special ed people.

Tina voiced her preference for separate special education classes, which were smaller, more intimate settings where she was able to work on overcoming her lack of confidence when speaking in front of her peers, a barrier she felt had prevented her from being more successful in school:

> I have a fear of standing up in front of people and talking. I'm trying to overcome that. That always got in the way because, if I had a presentation or something, I'd stay out sick the next day. I'd need to get out of it. A lot of our classes [resource] are small. I took resource government, and we had to do reports in front of the class. And the classes were like eleven people, and they were all your friends, you all had the same problems. And we started doing that and that made me feel better, because I knew they had problems similar to my problems. And then, after that, I could do it in front of twenty people. I kind of just kept on building.

Several students, including Tina, believed that students need and want varying amounts of support at different times in their school careers. She reflected that different settings were appropriate for different levels and types of needs:

> In high school, I think you need more [resource help] because you have exams. And I don't do good on test-taking. So, my freshman year, when I took my first exam, I completely bombed it. And then, the next couple of years, they made me take exams with them [special education teachers], and they'd read it to me and talk me through it.
>
> I think if you need the help, you should – it depends on how much help you actually need, though. Like if you need a lot of one on one with the teacher, you need to be in a resource class. And if you can do good with the class, and two teachers, that would be okay if you were in the co-taught class.

Devin also saw his special education needs vary at different points throughout his school career:

> There were some times during part of the school year that I felt like I wasn't in it [special education] enough, and I needed more help. Then there were times when it felt like I'm in too many classes, or I just felt like I could take that class outside of resource. It kind of went back and forth.

When students' programs didn't meet their particular needs, it was important that they, or someone on their behalf, advocated for appropriate programs and services. Some students were able to speak up for themselves. Others, who were too shy or lacked self-confidence, needed a parent or teacher

to serve as their voice. An informed parent, familiar with the law and the rights of the student, served this very important role for the student.

Heather was an outspoken student who was able, repeatedly, to voice her concerns and advocate strongly for what she believed to be her rights. At times, she reacted very emotionally regarding her special education placements, which she believed were not appropriate to her needs and limited what she could learn:

> When I hit seventh [grade], I noticed that the math wasn't that excellent, they were really behind. I was very good in my math classes, and I had complained in math for the seventh and eighth grade. I was always asking them to put me higher. But they were like, "Well, we can't because we are moving at the other children's pace, not yours." I didn't understand why couldn't I just do different math problems and she teaches the other kids, you know? And she's like, "Well, I can't do that." Well, it made me really mad and upset. But I went along with it. And I'm like, I'm getting put behind because my teachers don't feel that all the other students can do it. And I knew I could do- but they wouldn't let me do it.
>
> But now I've made it that far, they have already put me in co-taught, because I told them. And I've been begging them to put me in a co-taught, at least a co-taught, so I'm not doing times tables. Cause it was too easy for me. I was getting frustrated because I was doing the same thing over and over and over every year, and it was making me mad. I couldn't handle it anymore. I wanted to get into new stuff and do math.
>
> This year they put me in transitional math. I'm getting A's on all my papers and tests. I thought it [special education] set me back far. I thought that I was way behind. And I still feel that way. Cause all the kids that are in my math class are like, "Oh, we already learned this." And I'm like, "Well, this is something new to me." And I think that I have been set back because of it – and it made me mad!
>
> When I was in eighth grade, I was like, "I want to get out of here." You know, if you get into high school, you'll never get out. But right now, I think the classes I'm in are good placements for me. I feel that special ed is one of my needs and I'm going to have to deal with it.

Some students reported having general education teachers who were insensitive and unaccommodating to their disability. Like the poet, Elaine, who

described "what it is like to try to read and get so confused or so embarrassed you can't stand it," Amanda provided an example of a teacher who was unsympathetic to her embarrassment when called on to read:

> In American English Usage, I don't think she really grasped the concept of what was going on. Like, she didn't understand why I wanted to be skipped in reading out loud. Or why I'd choose as small a paragraph as possible.

Other students recalled times during their journeys when their teachers were not aware of, or were unwilling to follow, the accommodations listed in their IEP, which was critical to the provision of FAPE. Tina remembered such a time:

> The teacher, he did it [upheld an accommodation] only because it was written and everybody had signed it. He didn't like it. I'd leave the room to go take my test in a quiet spot. He didn't think I needed to do it. And I don't know if it was because he thought that he had to watch me take the test or what, but he just didn't like the idea of me leaving and taking the test with another teacher. He always thought that I should be able to ask him any questions. But, I always do better taking test by myself, anyway. My marketing teacher couldn't understand why I couldn't do some of the packets with some of the other kids. But it was because it was so much reading that I needed more time to read and understand what I read.

Interviews with the parents led to the discovery that, whether their child required additional time in special education, a change in placement, or accommodations in the general education classroom setting, parents often had to be strong advocates and provide a voice for their concerns. Brian's mother recalled his experience in the sixth grade, which is representative of such situations:

> We just had an awful time with a couple of the regular ed teachers. It just pissed me off no end why they wouldn't listen to a special ed teacher! Duh! Then they paid lip service to us when we started screaming and yelling and requesting meetings with the principals and teachers and everybody. Then they'd say, "Oh, we understand. Yeah, we'll do that." And they still wouldn't!

Some students experienced problems even within the special education classroom setting. Like the others, Heather's mother took on a strong advocacy role when she confronted the school about using what she believed to be an inappropriate approach to teaching her daughter to read. She reported how she had to persist in her requests that they use a phonics program instead:

> I know my child fell through the cracks. Like me and John bumped heads. Because I've been arguing with him the whole point, the last three years. I argued with him about phonics. Because I strongly feel that it's going to work. And I know that he has her best interests at heart, but I'm her mother – so do I! You know, I want her to get it. Even if it's only one semester, I think it's going to improve her reading.

Devin's mother discussed watching her son struggle through the sixth grade with resource room services before he was provided with the additional support he needed in a more restrictive, categorical classroom setting:

> In middle school, they put him in resource room. In sixth grade, I watched him just flounder – C's and D's. And he'd been doing much better than that He just needed more one on one. We went to John and said, "This isn't working." So he was put into EMI and getting one on one. And things just really accelerated for him. He got caught up. He just didn't work good in resource. You know, the commotion, all the other kids, and really needed somebody if he had a question. He needed an answer pretty much right then, or he couldn't go any further. He couldn't go back to that problem.

Devin's mother described how she needed to advocate for him again once he reached high school, when his resource teacher failed to notice his academic struggles:

> Mr. Williams, we went through a time with him because Devin had failed some classes. And when I finally had had enough – because I'd been trying to get in touch and find out why is this happening, what can we do? Devin sits down and he's right to work - he doesn't require constant monitoring. So, Mr. Williams said he just kind of forgot about Devin and checking up on him. He failed one class and there was nothing. I never got a six-week or a midterm progress report. So everything just fell

through the cracks. After that, Mr. Williams was on the phone to me all the time. It just took the reminding, I guess.

Eric's mother also shared her frustrations dealing with teachers who failed to communicate with her about her son's schoolwork. She believed that more should have been done by the teacher to keep her apprised of Eric's progress and any difficulties he may have been having. She stated,

> We ended up where he was flunking science just before Christmas. No messages. I said, "I don't know about you, Mr. Black," but I said, "We had an agreement here that if there were any concerns with this kid, that I would be getting notes from the planner on how to address it. Or at least a notice that I needed to call somebody!"

Eric's mother stressed the fact that not all students had parents that could or did check up on them frequently, as she did. She worried about those students who could easily "fall through the cracks" because they lacked such parental oversight:

> And I guess I get back to – if they're not getting their math, then they need to have – not just for my kids, cause I run around behind them constantly – and I STILL slip up! But we have other kids in the system that we're not running around behind! And they're falling off the cliff and get no credit! WHOAA! "I tried to contact the parent." So – you couldn't contact the parent? Why didn't you try the next week? You know, if you have the masters (degree) and you're paid the big bucks, and part of your responsibility is the caseload, then I guess that's what it is! Okay- you've got twenty kids. The optimal effect is, the twenty assigned to your caseload are going to pass. But that's not necessarily true! Why isn't it? He wanted me to sign this child's planner every night. He could write any notes he wanted in there that would benefit him. I get no notes! I've been doing mine – you can check the kid's planner – it's all done!

Listening to the students and their parents recount their journey through the special education system, it became clear that access to appropriate programs and services was largely influenced by the students' ability to self-advocate. Students who did not feel confident or knowledgeable enough to give

voice to their own needs needed to have access to someone that could and would advocate for them. Knowledge of the law, the students' rights, the system of educational procedures, instructional methodologies, and available programs and services served as a resource to those who would advocate on behalf of the student. As Eric's mother noted, students fortunate enough to have support in the form of strong and vocal parent or teacher advocacy were more likely to gain access to appropriate programs and services.

Individual Educational Plan Team Meeting Participation

Opportunity for student voice: "It helps you get through life"

The Individualized Educational Plan (IEP) is the vehicle for developing each student's educational program, including special education programs and services, supplementary aids and services, and accommodations. Beginning no later than age fourteen, students as well as their parents receive an invitation to attend their IEP team meeting. It is at this meeting that students are provided with an opportunity to discuss their goals and future career aspirations. Educational plans intended to prepare the student for their post-secondary experience are developed at this meeting, based on student and parent input.

Our nine students each arrived at their IEP team meetings as the product of all of the circumstances and events they experienced since they were first identified with a learning disability and set out on their journey. By the time they reached this juncture, they had come to define and accept themselves according to the spoken and implied messages they received from others. They might have

felt comfortable with themselves, accepting of their disability and aware of what they needed to be successful. Or, they might have felt embarrassed and ashamed of their learning disability and stigmatized by their label, too paralyzed to access services. They might have felt like one of the group – or like an outsider.

All of these feelings and self-attributes played a major role in how and to whom the students assigned voice at their IEP meetings. Whether, and to what degree, the students chose to advocate for themselves or to rely on others to advocate for them was dependent on their knowledge and understanding of their rights under IDEA, their understanding and acceptance of their disability, and the resources they had available to them for support and advocacy. These variables were often interwoven throughout the students' stories as they related their experiences during their individual journeys.

Each of the students told a story of someone who played a major supportive role in their lives. Most often, this person was a parent, but many times teachers or individuals such as the school psychologist also gave their time and provided extra support to the student. These trusted adults often provided support and encouragement to students by helping them with their assignments, explaining and clarifying concepts for them, and encouraging them when they became discouraged along the way. Parents spoke of the countless hours they devoted to helping their frustrated children with homework. They often soothed their feelings of isolation and loneliness. Advocating for accommodations, programs, and services appropriate to the students' needs were also roles these

adults adopted in support of the student. The students described the ways in which these adults took on a great deal of responsibility for helping them to gain access to necessary programs and services and to make key decisions regarding life goals.

Tiffany stated that her mother played the most prominent role in her life:

> My mom almost always goes to my IEPs because she cares what happens. She is very, very supportive of me. School is a priority with her- I have to do my homework. My mom works nights, but helps when she can. I can call her at work with questions and she'll try to answer them.

Devin also gave credit to his mother for providing the guidance and support necessary for him to overcome his disability and succeed in school:

> I feel like she's been there ever since I was young and ever since I started school because she's been the one that's spoke up the most as far as my mom and dad. And she's been the one that's been there the most for me through all of school. Probably by about the fifth or sixth grade, I really knew that if I needed help on anything, she'd be there for me. Because she'd always been there and always helped me with schoolwork.

Like Tiffany and Devin, Heather believed that her mother provided her support in several ways. Her mother quit her job so that she would be available to help Heather with schoolwork. She was a very vocal advocate on her daughter's behalf, and encouraged Heather to develop and exercise her own voice. Heather stated that she and her mother had a very close relationship:

> I'm very in-tuned with my mother, and I tell her how my feelings are toward things, and she tries to help me understand it. Or, if she feels that I'm right about something, then she'll have a talk with the teachers. My mother and step-dad worked 24-7. But my mom stopped working and now she's an at-home mom. So, if I needed help, yeah, I could get help. My mom, she's taught me to advocate for myself. You know, "You want to do this, and you put your mind to it, you can do it!" And that's what I've done.

Heather's mother recalled a conversation she had with her daughters during which she shared her feelings of concern and care for them:

> You think just because I don't know your favorite color, or what your favorite things are, and I can't keep up this week with what was last week, you think I don't know you. But I've spent my entire life studying you. I've basically been fascinated with the way your different personalities have developed and who you are, who you're becoming. So, I have really been paying attention to the important things, and that's who you are.

Tracy spoke of the ways in which his parents demonstrated their support for him by following through with consequences when he didn't comply with their expectations:

> My dad and my mom want to make sure I succeed, cause they make sure I don't skip or anything. If they find out, then I'm grounded from my car for a day. And they just want to make sure that I get a good grade-which is a good thing.

Eric explained how his parents were a strong source of emotional support; "They just try to comfort me – they just say, 'Oh, no, you'll get through this. It will be fine. You might feel different, but you're really not.' They help me and encourage me." His mother admitted that sometimes the emotional and academic support to Eric came at the expense of her younger child, Nate, who also had a learning disability:

> I was reading to him. I was playing games with him. And then, because I was under so much – I had to pay attention to Eric's homework, read it with him, do all this kind of stuff – I was trying to pick up all the pieces in the middle- I lost Nate, the next kid. Oh, Eric, we even paid for summer reading programs for him which, as a single parent, completely broke me.

For some parents, the fact that there had been another family member, or members, with a disability served them as a resource, contributing to their familiarity with the disability, the limitations it imposed, and the student's rights

under the law. It also helped provide them with a clearer vision of the roadblocks their child might encounter on their journey as a special education student. This, in turn, influenced the nature and degree of their oversight of their child's program as well as the expectations they set for their child. Five of the students, Jim, Brian, Tina, Tracy, and Eric, and their parents, told stories of others in their families who had the same, or similar, disabilities and the influence that had.

Jim told about his father, to whom he strongly related and who also had some learning difficulties in school. Jim described how his dad made it known that he expected Jim to graduate:

> My dad...had a lot of trouble reading. He couldn't read through the phonics method, and I have the exact same problem. So, I think he had LD as well, but since they didn't diagnose it much back then, he probably wasn't diagnosed with it. I think he has the same problems as me.
>
> He gave me a graduation present- a car, cause I needed one. And he said, "Well, this is your graduation present. I'm not signing over the title to you until you graduate." So that kind of like shows you he's expecting me to graduate. And he's told me about it before and stuff.

Jim's mother addressed the fact that she, too, had a reading disability, which helped her to understand the difficulties her son experienced:

> When he was learning how to read... he doesn't have the sounds the same. That's what my dad said, "The same as you," - cause I don't hear them right either. Cause we also had reading problems, so it's like hereditary. And spelling is very difficult for us.

Brian's parents were greatly influenced by the tragic fate of his uncle, who had a similar learning disability, and were zealous in their support of their son's education. They spent years reading to him, taking him to tutors and trying to "build him up and support him in the areas where he was doing better." Knowledge about her brother's disability and it's negative impact on his life

served Brian's mother as a resource she used to help her understand Brian's struggles in school and to advocate for him:

> Part of the reason that I knew what was going on with Brian is because I had a brother that was very similar. Almost the same learning disability. So, I could see almost the same thing happening to Brian that happened to my brother. And my brother ended up very, very messed up. Very messed up: a drug addict, criminal, murderer – then committed suicide. I was just scared to death to see that happening to my son, so I was really pushing for him to have services.

Brian's mother affirmed that she did whatever it took to help him be successful. This included making sure he got to school, even on days he refused to go. Many nights were spent doing homework, reading him his materials, and typing his papers. His mother described her efforts to support him with his schoolwork and to set future expectations:

> We just stay on him! I didn't work because of him. I just work part-time, so if he wasn't going to get on the bus, I would drive him to school. I would just keep after him to get up and, you know, mom is going to drag him kicking and screaming through school the whole way. Because I just refuse to let him fall through the cracks and drop out, not get it, not get decent grades.
>
> We just have to help him. We've done lots and lots of homework together. If the reading level is very high, he can't get through it very easily, so I read it to him and ask him the questions. I make him write a couple, then I write a couple, and we'd go back and forth. If he gets too frustrated, I'll get on the keyboard and say, "Okay, just talk to me. Tell me what you want to write." And I'll type it for him.
>
> He's pretty much focused on hands-on kinds of things, some technical programs and technical college training, and we have encouraged and encouraged and encouraged! He knows he has some options other than the four-year program. I would love to see him at least do two years. He knows that we have expectations that he do something beyond high school.

Brian recognized that his parents had always been there to support him, and recalled many occasions when they intervened on his behalf for programs and services:

> My parents wrote to the head of special education, Mr. Paterson. They wrote a letter to him, and he made the principal do it, tell the teacher so then he had to read it (the test) orally. If the teacher didn't give the accommodations that we got, they (my parents) would always be there, calling or trying to get them to do it – or get me into special ed classes or changing my schedule, or something like that.

Tina believed that her mother was able to understand her learning disability because her father had always struggled with reading. She felt that, unlike many other students, she was lucky to have parents that truly cared about her:

> A lot of parents just don't care about their kids. I got lucky, because my mom cares a lot about us. So does my dad. I think it [student success] has a lot to do with parents. I don't think the school really can change anything. I think it has to be more from the parents. Like, if parents would not say, "Oh, you can drop out," but say, "You go to school or you get out," I think a lot of kids would stay in [school]. I just think that support from parents is important.

Tina's mother described how the failure of her relatives, who had learning disabilities, to finish school motivated her to set high expectations for her daughters and to fight for their rights:

> I found out that on my father-in-law's side, this runs in the family. All of his relatives on his side have these kind of problems. I have three daughters. Tina does [have a learning disability], Beth does, and Brittany was actually kicked out of resource last year, which I'm going to fight.

Tracy's mother described her family's history with attention deficit disorder and her expectation that Tracy would complete high school:

> His dad also has ADD. He does not have hyperactivity, though, so it was many years before we related the two. Our middle son has ADD without

> hyperactivity, so we had him diagnosed when he was, I think, second grade. Same symptoms as my husband had. And so, to realize that we had three people in the household with ADD...
>
> Even with the two older sons, they have both graduated from high school – kind of by the skin of their teeth – because they didn't put forth a lot of effort. But yet, there was no talk of NOT graduating. And I'm so glad that Tracy never gives me a problem with going to school.

Eric's mother acknowledged that she also had a mild reading disability. She spoke of the need to get Eric through school with the appropriate classes so he could graduate on time with his peers and get into college:

> I struggled with reading, and if anyone would have paid attention, they would have realized that I had an extremely low reading rate because I had eyesight problems.
>
> To be able to put him into college, the math is so important. It's a complete brick wall until they can pass that math. So, he has to go forward. He can't just stop and say, "It can't work." And it's going to be touchy, like I say, with reading and comprehension more than what algebra was. You're not going to have a successful senior that's twenty – it's not going to happen. It turns into a liability rather than an asset to keep him here – so, I've got to push him through.

Eric's mother, a college graduate with a teaching degree, insisted that, no matter what, she would push him to get at least a minimum of college completed before going to follow another path, such as enlisting in the Navy:

> I definitely expected [Eric to complete high school]. College – of some sort. Whether it be a certificate class, an associates, or he can do a bachelors- it just might take him longer.
>
> I told him, "If you want to go to the Navy, first you have to do two years at LCC [a local community college]. And then you can go into the Navy." A lot of it comes because I went to college. You're not going to get sidetracked into the Navy with a learning disability with zero credits underneath your belt from a college course. I mean, even if he doesn't complete a program – of course that wouldn't make me happy – everybody wants their kid to have masters degrees today- I'm not crazy! But, on the other hand, at least get him into something where you've got

his confidence level where if he does go off to something else, that his confidence level is still there to return to.

My mother told me that I always needed to go to college. Cause if not, I was always going to get somebody else a cup of coffee who made three times more than what I made. I watched her do it until she got her bachelors degree. My dad had a degree. Well, they're [my kids] going to do something!

As the students and their parents told their stories, it became evident that whether or not parents had been able to achieve their own aspirations influenced their role as advocates and their commitment to see their children succeed. Numerous citations strongly support this assertion. Tiffany related,

My parents want me to finish high school. My mom never got to finish high school, and she doesn't want that to happen to me. She didn't finish her degree and she's stuck in a job she hates. She doesn't want that to happen to me. My brother never went to college. He's working at Taco Bell, and my mom is disappointed that he never went. School is a priority with my mom. I have to do my homework. If I don't do it, and my mom finds out, I get grounded.

Tiffany's mother spoke about having to go back to get her high school diploma through adult education, and her desire to see her daughter finish high school:

I did stop [going to school], but I did go back, and I graduated through adult education. I would like to see her do whatever she wants to become. We always go to that, "Whatever you decide you want to become, I will support you and back you, 100%. The better your degree and the better you do in school, the better you're going to do in the work field, and the better paycheck you'll bring home." She's always talking about all the things she wants. So I told her it's very important that she accomplishes this now. I've stressed that [finishing their education] very highly with both my kids.

Jim's mother spoke of her expectations that Jim would, of course, graduate from high school, as had everyone else in her family:

> For me, not graduating is NOT an option. He'd be the first one in my family. My great grandmother was a schoolteacher. My grandma, my grandpa, my mom, my dad, my stepfather, everybody! All my cousins! And no, for me, it's not. There have been times when he said, "I should just drop out of school and work, so I can make more money." For me, if you're living at home and you haven't graduated? You graduate! You go to school!

She also divulged her conviction that Jim should go on to college so that he, too, would not be "stuck" in an unfulfilling job:

> I would like to take some computer classes, just to try to get out of there (her present job at Subway). I mean, I got to get out of the restaurant business! Really, the biggest thing I want for him, is for him to be happy, and for him to go to college. I want my kid to go to college! It makes such a difference for them. I've always said, "Look at your dad and I. Do you want to be working in Subway when you're forty years old? Go to college!" I thought it would make a big difference for him going to college, and he did need to be pushed.

Tina described how her mother's own life goals and a family history of relatives who had not graduated shaped her mother's expectations for Tina and her two sisters who also had learning disabilities:

> My mom graduated from high school and she went to college for a year and a half, I think. My mom was going to work on computers – she never did that. She quit going to college.
>
> My mom wants all of us to graduate. And we don't have a choice. I finished. My sisters will finish. It's just a family thing. We've always been taught you either go to school or you get a job and you support yourself. I think that was good that my mom did that, because my cousins – I'm the first one to graduate out of my family. And I have five or six cousins that are older than me and their parents never said, "You either support yourself and get a job, or you go to school." And they all dropped out. And with us, it's like, her saying that meant that we HAD to do it. One or the other. And that was pretty clear.

Tina's mother recalled a conversation with her daughter about her expectations:

> We talked about it one day, and I told her, "I'm so proud you're graduating!" And she told me, "Mom, you never really made it sound like I had a choice! You told me I had to graduate." I'm real big on that one,

> cause my nephew has that [learning disability] and I told my sister, "You don't teach them to make excuses for it. You have it – deal with it!" You're getting help, just deal with it, you know. If you know what it is, then you know your weak parts and you work on them, they'll get strong. And if they don't, you at least know what they are and you're learning how to work with them instead of fighting it all the time.
>
> Graduating – that was my biggest one [goal for Tina]. I'm pushing her really hard for college cause, being the baby coming- I had her at sixteen- I said, "You know, honey, I gave up college to stay home with you. And now look at us. I'm working three jobs to try to make it, because I wanted to be with you when you were too little to even remember that I was with you." I said, "So, leave the baby for those two days a week and go to college, because in five years, when he's old enough to realize you're not there you'll have a good job and not be working three jobs." So, I push that on her a lot.

Heather felt that her mother held the same goals for her as she held for herself: "I think she wants the goals that I want. And those are to graduate high school and then go on to being a lawyer." She recalled that her mother had to drop out of high school in the ninth grade "because of family problems," but eventually graduated with a diploma and went on to some college. Heather's mother talked about her daughter and what she hoped her future would hold:

> She's a determined one. I mean, for the most part, my whole thing is, don't limit them. See what they can do. Just like everybody else. I don't believe you have to go on to college. She's been exposed. I ran my own business – I have off and on over the years, of one sort or another. So, she's aware that she can become an entrepreneur herself with coming up with the right idea and the right approach. I'm a true believer in higher education. I believe it can never hurt and you should always seek it. I think, regardless of what you do, you have to make the choices yourself.

In addition to the students' parents, teachers also often took on the role of advocate or "gatekeeper," facilitating the student's access to special education programs and services. Parents and students provided many accounts of teachers who had provided critical support to the student. For Jim, who

struggled in his relationship with his mother and whose father-- his main source of emotional support-- lived far away, teachers and the school psychologist played an instrumental role:

> My mom didn't go to my IEP this year or last year. I don't really listen to her. It's hard. She doesn't really involve herself that much in my life, so it doesn't really affect me. My teachers help – Mrs. Woodard helps.

Jim's mother admitted that she no longer felt it necessary to attend Jim's IEP meetings because "nothing's changing." She recalled that the school psychologist provided a great deal of support to Jim during some stressful times in his childhood:

> I know that when he was having a lot of problems, he spent time with John Reno – and there was another one in Ellsworth Elementary that was really good with Jim, but he retired, and I can't remember his name. But he was great!

The parents of the other student participants in this study were very supportive and involved in their child's education. Many of the students were fortunate to have additional support available to them from their teachers. Brian's parents, who were relentless advocates, gave much credit to his teacher, Pat, for contributing to his success:

> I don't know if he realized it or not, but I think Pat's a huge help, encouraging him, pushing him a little bit, the things that they cover in the class that she has with him. Just the way even she talks with him, interacts with him.

Other students, such as Amanda, describe teachers who always seemed to "be there" for them:

> Mrs. Briar took me under her wing and just kind of made me have a study hall. I had her in sophomore year with my math teacher. I had a class in there with her and then she just kept me up last year.

Amanda talked about how her mother and her brother attempted to help her with her homework, but her teachers were the ones she could rely upon the most:

> My mom, when I was in fifth grade, tried to help me with math, and she couldn't do it – it was so different from hers when she was doing it. I know my brother helped me out a little bit, but that was about it. I just asked my teachers. They were always around. Mr. Williams is a good guy, you know what I mean? If I asked him for help, he'd do it that way. Or if I don't understand something, he'll stop and do it again till I get it, so...Mrs. Briar was there- she was in the class. So, if I had a struggle, she'd help me. My teachers helped me out with getting stuff done and doing it right.

Amanda's mother also credited much of her daughter's success in school to the fact that she had helpful teachers:

> She's always loved her teachers. That's, I think, the key, right there. She's just had great teachers that build her self-confidence in ways they're supposed to!

Like Amanda, Devin believed that in order for students with disabilities to successfully overcome obstacles they encounter on their journey through school, they needed to cultivate relationships with their teachers:

> If you get along with your teachers, you'll be fine. They'll understand and know and help you through it. But if you don't know your teachers and don't interact and talk to them and tell them what's going on, you're going to have a harder time to get through that hard period.

Devin's mother reiterated her son's belief about his teachers. She saw her son begin to develop self-confidence and make the most gains in school once he was placed in Susan's classroom, "blossoming" under her care. Devin's teacher, Susan, helped him to accept his disability and assert his voice in determining his educational program:

> Susan was great with him. She was a big sports fanatic and they just clicked from the beginning. She really took an interest in him. She'd come

> to his soccer games every once in a while. And they had a rivalry over the MSU [a local university] games. And we had hockey tickets and she had them, so they were just – Devin always learned. He could memorize sports facts, yet he could read something and not remember what he had just read. So, when you catch his interest like that, he just seemed to thrive and she hit on that – had that common interest. So that seemed to really be the turnaround time. When he got to Susan, I think she really gave him a desire, maybe, I don't know. She made him like going to school. His confidence just really changed when he hit ninth grade and went to classes with Susan. He had Susan in ninth and tenth, and by eleventh grade, he was pretty much speaking for himself. I didn't have to do much of anything for him anymore.

Tina believed that her special education teachers provided a great deal of encouragement and assistance, acting like a cheering section, and serving as her voice to run interference with her general education teachers whenever necessary. She described a situation where she felt like "giving up," but her special education teacher continued to encourage her, providing her with the motivation to stay in school:

> In my eleventh grade year, I got really frustrated and I wanted to drop out. I was tired of school – senioritis way too early! I had marketing, and that class was just so hard, and I wanted to drop out of it. My teacher, Mrs. Hall, sat me down and told me, "You really need this. I know with the right help, you can pass this class." Without her helping me, I probably would have dropped out of it. We did packets, and she made copies for me. Any tests that I took, I took with her and she read it out loud to me. She talked to my teacher about how fast they go- cause it was quick, one packet in two days, and I need a week. And she allowed me to work on it in her class, and she was always there to help me with it.

Mrs. Hall also coached Tina in developing her own voice so that she could advocate for herself with a general education teacher who wasn't following through on providing the accommodations listed in her IEP. Because of her support, Tina was able to self-advocate independently the following year:

> She helped me type up a letter explaining my learning disability and all the requirements I needed, and then I gave it to him. Then he was more

> understanding. So, I think you should be out in the open with all your teachers. Like, first I had to say, "Hey, I have this disability and I'm going to need some requirements." And I think if you're open, it gets better. She (Mrs. Hall) helped me do it my junior year. And I did it my senior year. I think the letter helped a lot. And I think if they help them do that when they're younger, maybe that would keep them going.

Tina found an additional source of support in her teacher, Mr. Williams:

> Mr. Williams has always been there. My freshman year, I had him in one class, and we got really close. And anything I needed help with, he was always there to help.

Like Tina, Tracy had a teacher, Mrs. Woodard, who worked to reinforce Tracy's success in school. Tracy related an incident when he "almost didn't make it" except for the help she provided to him:

> I was failing three classes, last quarter, and to bring that up for the actual whole semester, I went in on a Friday, which we had off. I went in and worked with Mrs. Woodard, and got the stuff done during the period, and turned something in which allowed me to pass that semester. And if I hadn't gone in that day, I would have failed it.

Eric described a favorite teacher who made school fun and was also very motivating:

> My special ed teacher – I had a great guy last year- when I was a freshman, which I wish I still had. Like Mr. Roberts – he was SO good! Everybody liked him. He was just – out of everybody else, I think he was my favorite teacher so far in life. He just made us understand it a lot better. He tried to have fun doing it. He'd take us sometimes, like we'd go down to 7-Eleven and would just talk a lot about what we did that day, and he'd give us little pop quizzes on the way. It was just so much fun. He made everything a lot funner. He was awesome. I wish he was here this year.

In addition to providing strong support and encouragement to the nine student participants, parents and teachers also set high expectations for their graduation. This connection with a very supportive adult served the student as a resource, or social capital, that supported them in taking advantage of their

educational program. In some instances, students entrusted their teachers to act as their voice and speak on their behalf. In other cases, this support helped the students to develop their self-confidence, to accept their disability, and to self-advocate for their rights.

The ability to set goals for themselves seemed to be directly related to the ways and degree to which students chose to self-determine, to exercise their voice, and to take an ownership role in developing their individualized education plan. All nine students saw themselves as definitely graduating from high school. Some identified potential roadblocks along the way they might have to overcome to achieve this goal. Most (seven out of the nine students interviewed) had an idea of what they might like to do following high school. Students and their parents were asked to reflect on the likelihood that the students would achieve these goals.

Tiffany believed that she would surely graduate on time, and that nothing would hold her back:

> I want to finish and graduate high school with my friends. I don't think anything will get in my way. I will definitely graduate! I made up my mind- I'm not going to "slack off" again. If I need help, I'll ask someone, like my teachers or my friends.

When asked about her long-term goal, she stated, "I've always liked animals. I don't know about computers – I just like working on them." Tiffany's mother believed that Tiffany was now more self-directed and motivated toward achieving her goals. She had seen her become a more serious student, excited about the fact that she "tested out" of special education:

She knows that in order to be able to go to college, you have to finish high school. She was getting A's and B's, she's using her time more wisely, which is the first time I heard that at a conference, I think, ever. And she seems to be interested, she participates more...She came home all excited, she was jumping up and down. "You'll never believe it – I tested and I don't have to be in a resource room anymore!" And I said, "Well, great! Congratulations! This is really fantastic!"

I think that now that she's doing so good, she feels proud of herself. Her outlook and her perspective for school has just soared tremendously. She will NOT miss school! She's doing so good- if she starts falling, she might slip back. She didn't have as good self-confidence. But now, it's like she's on cloud nine. She just knows she can accomplish it.

Jim also had high aspirations following high school, which he was confident he would accomplish:

I want to move into a high science career. I want to be a veterinarian. I want to do aviation next year. I'm kind of bouncing between the two. So, I don't know what I'm going to do yet. I like science. I'm taking anatomy and physiology right now. I keep moving myself up. Next year, I'm doing some more science classes. Well, I'm doing a lot better this year. I slacked off freshman year, and last year I messed up some. This year I'm doing pretty good. I'll probably go to LCC [a local community college] first, because I need to get in somewhere, and get my college grades up. I want to go to Michigan State [a local university], but I don't think they'll accept me in the veterinary school program. I want to get my license and open up my own clinic, and I'll need business classes.

Jim's mother stated that Jim now sees his special education program as necessary to support his goal of going to college:

College and things – that's why he doesn't want to get out of the program [special education] now, where he did want to be out of the program at one time. He really wants to go to college, and I keep bugging him. He says that nagging kids does not help get grades up, and that they have to want to do it. Which he does have a point. Because he blew it off, and didn't do well until he wanted to this last couple of years. And he finally – he says his teachers say- he is finally showing his true potential. Maybe when he started to see the money that would be there. Because, he wanted to go to college, but he never thought he could, financially. So I guess that, maybe it was, "Oh, there is a way I could go" type of attitude. Maybe he just grew up some.

Brian, only a freshman, did not really know what career field he might want to enter following his graduation. He knew only that he didn't want to end up in a boring, low-paying job:

> I don't want a bad job – fast food, or something like that. Not making any money, living in a trailer...that's something I REALLY don't want to do!

Brian's mother worried that unless he was able to complete his work, his grades would suffer, affecting his ability to graduate with his peers:

> Brian wants to do well, and he wants to have a decent grade point average, but if it looks like too much- it's too scary and too much work, he'll let it slide. Anything that looks larger or is a lot of writing, he'll "forget" about it, pretend he doesn't have it and put it off and put it off. He'll put it off so that it gets worse and worse and worse, so that – something that if you took it piece by piece by piece wouldn't be too bad- he leaves this big thing to the last minute. Well, maybe then, all of a sudden, he had several more big things to do, and all of sudden you've got a pile of homework. He gets totally freaked out – can't even focus on it.

Amanda, a recent high school graduate, was determined not to end up like her sister, and intended to go to college and major in a program for physical therapy:

> I saw my sister drop out. She dropped out and went to Alternative [Education]. She's working in M [a local store] in the cash office, and that's not what I want to do. Cause I'm working at F [a local store] and I don't want to work there – do that for my life. I'm going to go to LCC [a local community college] for massage. I'll go to Central [a four-year university in Michigan] and then Davenport's [a local business college] got one now, too [program for physical therapy]. And then there's also Grand Valley [a four-year university in Michigan] –they've got the greatest one in Michigan.

Devin, recently graduated from high school, had dreams and goals for himself that far surpassed his mother's expectations. He set about on his own initiative to "make it happen":

> I was looking forward to something in business. I really haven't taken the classes because that came up for me towards the end of my junior year. My brother went over to Japan and wants to go into international business. I don't know, it was kind of him [that influenced me]. I've always wanted to be on the top and own something. I started looking at school as, "Yes, I'm going to make it through"- even if there are hard times.

Heather, a freshman, was one of the most goal-oriented students interviewed. She appeared to know her own mind, and didn't see anything getting in her way. She knew what she had to do in order to be successful, and she indicated that she was willing and determined to do whatever it took to reach her goal:

> I do plan to graduate high school and go to LCC [a local community college] or MSU [a four-year university in Michigan] or something, a four year college, then go on to Cooley [a law school]. I put my friends to a limit and I just started studying a lot more, reading a lot more. The reason I put a lot more work into myself is because I couldn't take it to myself as failing. I felt like if I was in special ed classes, I was failing myself. And that really hurt me. So, I was like, you know, "You can't let yourself down." So you're going to work harder, you're going to get less friends. Well, I'm saying stuff like, "I can't talk to you right now, I have my work" and all this stuff. And I've lost some friends for doing it. And, I was like, you know, if they really want to be my friends, they'll respect my wishes. And my wishes were to let me get higher up in what I have to do, and then I can go out and have fun, but not until then.

Tina's goal was to be a fashion buyer for a retail store. Her mother spoke about Tina's aspirations and the many hardships she and her family had endured that had been potential barriers to her recent graduation:

> She's excited about college. And she likes the idea of going to college. She wants to be a buyer, and it's a really hard market to find anywhere. It's really hard to find out where you go until you ...get into it. I think she'll make it through college. But, we just found out that the college that she's going to doesn't have special ed accommodations.
>
> Her dad just went to prison, so that was huge. She's had a lot of hardships in the last five years. My father passed away. A week later, my aunt died. My grandfather died, and the day before that, my cousin killed himself. My

> grandmother on the other side died. My brother-in-law lost his arm and my mom was just diagnosed with cancer, and it doesn't look good. So, she's had a handful- other factors, home things going on that I thought she might drop out.

Tina stated that one of the reasons she felt she was able to stick with her goals was her mother's expectation that you just don't give up:

> She's said, "If you want it, no matter what, you can get it. There's no excuses." And she's done a lot. She's lived her life by she can do anything. I like the way she says it. She has that goal, that saying, and she sticks to it. And I agree with what she says, because if you want something bad enough you will really get it.

Tracy was also committed to following his dream of becoming a musician:

> I'm interested in music education, instrumental – everything. I first dreamed of being in a rock band and everything. But now I still want to do that, but I want to learn composition and everything. What I want to do is, like I'm into marching band right now- so I want to go to Michigan State [a four-year university in Michigan] and play there, and possibly get my masters. Eventually, if it's possible, I want to go to an actual music college and learn about composition.

Tracy regretted that his lack of focus earlier on in his educational career caused his grades to suffer. Realizing how important his high school studies would be to his college career, Tracy described his drive to redeem his grade-point average:

> Last year and the year before, I was always just like, "What do I need to do all this stuff for?" Cause I just pretty much planned on being a rock star or something like that. I wasn't even really planning on going to college. So, then I'm just realizing that I can't really go anywhere cause I need to learn as much as I can about music before I can actually make stuff that sounds good. I just realized that, and finally I got a reason to work for a good grade. Cause I'm trying to get into Michigan State. It has to be us that realize that, because most of the time, we don't really believe it. And it took me a long time to realize that I need to go to college and do all that stuff.

Tracy's mother agreed that having goals was "really good for him". She noted:

> He's made a lot of improvement. It's been a struggle along the way, but I can see a lot of growth. And I can bet the goals he set for himself- he didn't have those goals, I don't think, last year at this time...He's been able to talk- a lot, I think- at band camp. He talks with these people, one on one, and gets an idea. Tracy wants to go into the same field as this gentleman, music composition.

While Eric did not discuss any goals he might have set for himself, his mother mentioned that Eric wanted to go into the Navy following his high school graduation. She believed that Eric had the ability to make it happen:

> He'd really like to go in the Navy. So I told him, "If you want to go to the Navy," -that's I mean, he's only in the tenth grade- "first you have to do two years at LCC [a local community college]. And then you can go into the Navy." Eric will make it because Eric is driven. He's not going to be a problem. That's just his personality.

The ability to set goals and the drive to self-determine largely influenced the role the students took at their IEP team meeting. Students who had solid goals, like Heather, were more likely to take an active, participatory role. Students whose goals were less developed were not as likely to feel the need to speak up at their IEP team meeting, and were more likely to let others serve as their voice.

<u>Assigning voice: "I am not trying to sound stuck up" but, "They will never understand the feeling"</u>

The degree to which the students became involved and participated in their IEP team meetings and the roles that they played varied widely. Student and parent attitudes differed with regard to how important it was for the student to have voice in planning his or her education. In addition, student responses to questions regarding issues of self-determination revealed that the term "voice"

was interpreted differently by different students. To some, voice took on its common meaning, that of the student's own voice. For others, voice meant the voice of a strong advocate, such as a parent or trusted teacher. While some of the students believed it was critical that they attended their IEP meetings and advocated for themselves, others played down the importance, and felt that the IEP meeting was more a formality and mattered little in their education.

Some students, like Tiffany, perceived these meetings as intimidating and believed that teachers did not really encourage students' active participation:

> I went to my IEPs since middle school. I mostly just answered questions. My teachers and my mom make most of the decisions about school. My mom almost always goes [to IEP meetings] because she cares. I feel nervous when I'm there. Pretty much, the teachers fire questions at me and I answer them. Teachers should ask students what they want, and listen to their ideas instead of just talking and asking them lots of questions.

Tiffany spoke about a situation in middle school where she was unhappy with a decision that resulted in her having to miss her favorite subject, science, in order to access a special education resource study skills class. She admitted that, despite the fact that she did speak up and address this issue at her IEP meeting, the situation remained unchanged:

> I did not like missing science in middle school, so I asked about it. They told me that they alternate social studies and science for study skills. But I got two years of social studies and only one of science. And I was upset!

Amanda admitted that she was reluctant to take charge of her own IEP meeting, lacking confidence, and feeling shy and uncomfortable in that role. She believed that her teachers were better equipped to make critical decisions about

her education, and she trusted them to do what was in her best interest and to act as her voice:

> My mom makes me [go to my IEP meeting]. If she's not there, then I'll go. The only one I remember going to was the one in high school. Mr. Williams, or whatever, my case manager [was in charge of running my IEP]. They [teachers] just asked me questions. Or see if I agree or disagree with stuff. I just sat there.
>
> I was in front of my teacher. I didn't want to get her mad or anything. I think everyone has their weakness in talking about their feelings and stuff. It may be okay for someone and not be okay for the other person. I mean it doesn't really matter. It doesn't bother me that much. Some people might be shy.
>
> My teachers [had the most say in setting my schedule]. I just knew they were doing it for my best interest, not just because. I don't think it would be best [if students ran their own IEP meetings]. Teachers know what to say and how to say it and what they need to talk about. And how to overview things. I don't think kids would – they would like it, I mean the sound of it, "running their own meetings." But, actually doing it, I think they'd be a little more embarrassed about talking about themselves – talking to a group is more intimidating. And it might be embarrassing to tell your teacher, "Well, I think this." I don't think kids could do that. Not in high school.

Observations made at Amanda's senior year "exit" IEP supported her account of her role and participation. Amanda was present at the meeting, but did not actively self-advocate. She answered questions regarding her career interests and plans, but in no way did she "take charge" of the meeting, which was led by her case manager. She did appear somewhat shy and remained quiet as the adults talked around and to her. She did not expound on any of her brief responses to questions directed at her.

Unlike Tiffany and Amanda, other students believed that they *should* be actively involved in their IEP meetings. Each student portrayed his or her individual passion for self-advocacy and self-determination. Some were content

to have their parents function as their voice, while they shared their opinions and desires from the sidelines. Heather was one such student who needed to share the role of advocate with her mother:

> I'm very in-tuned with my mother, and I tell her how my feelings are toward things, and she tries to help me understand. Or, if she feels that I'm right about something, then she'll have a talk with the teachers, and if they have the same understanding, then that's what happens. Cause in eighth grade, I really badly wanted to get out in math. And I wanted to get into a higher English class and I did that.

Heather did not believe that her voice had much power. She felt that, ultimately, her educational program and class schedule were decided by her teachers, regardless of whether or not she attended her IEP meetings and made her concerns and wishes known. She felt strongly that students should be given more voice and ability to self-determine:

> I feel that they say and do what they're gonna do and, no matter what, you're gonna like it. That's how I feel they do IEPs. It doesn't matter what your opinion is, and if they don't agree with it, you don't get it. And I think that they should let kids have more opinions and more voice, saying what they want to do. But, if they start dropping grades – don't let them drop the whole semester, but give them at least a month. And if the grade drops, you take them out and give them what they need. What you think they need.

Heather also felt that the school discriminated against students in special education by restricting their opportunities for learning and choice. Unlike the other students who were able to choose their own schedule, students in special education were able to choose only one of their six classes each semester. She explained her views:

> I think that they should have given me a book telling me other classes that I could take. And I would pick out my classes for my schedule instead of them sitting there saying, "Oh, you're getting this, this, and this," you know. And I didn't have a say in it. No matter what I'd have said, it

> wouldn't have mattered- they're still gonna put down my schedule for me. And I only get one class that I get to choose for. And I don't like that at all. I think it's unfair! All students get to pick their own classes. Only special ed kids have to pick *one* class. I guess they feel that other kids can do for their own, and us special ed children can't do for our own. I disagree with that.

While Heather insisted students should be given more voice in the educational decision-making process, like Amanda she did not believe that they should be pressured into taking control of their meetings. She admitted that she was not sure of what her role should be at her IEP meeting, what was or was not appropriate for her to say. Regarding a special education class aimed at promoting student self-advocacy, Heather articulated her belief that forcing a student into a leadership role might just intimidate them to the point where they pulled back:

> I wasn't too sure about my IEP because I wasn't sure of what I can say and what I can't say, and what I can do and can't do, you know. So I was kind of leery about it. But I feel I should have said more than what I did.
>
> Pressuring a kid to do what they don't want to do is kind of hard, because she'll (the teacher) make you stand up and do this. You know it's kind of like, what if I don't want to be in charge of myself? Which is most kids. Yeah, most kids, they say that they do. But they can't – they don't like making up their minds. They can't without somebody else's doing it. They are taught to do that. My mom, she's taught me to advocate for myself. You know, "You want to do this, and you put your mind to it, you can do it."

Tina took a stance similar to Heather, believing that, while she was her own advocate, her mother played a key role, acting as Tina's voice at the meetings:

> I didn't go to my first one [IEP meeting] until a freshman. I think it was my mom and my teachers [who made most of the decisions about my education]. My mom understands a lot of how it is and everything, cause my dad doesn't do good in reading. So, she knew what we needed. She'd ask us about it and we'd tell her. She would just tell them.

> I did a lot of it [making the decision for what classes to have]. My sophomore year, I signed up for biology- and I don't do good in biology at all. I did the co-taught. I asked them if I could have two teachers, and they did it for me. So like in math – I've never had a problem with math- so I told them I didn't need the co-taught [two teachers share the teaching role] in that one.

Tina felt that as she grew older, her role in the IEP meeting became more important. While she relied on her mother, to some extent, to advocate for her, she also believed that the students themselves knew best what type and amount of support they needed from their program, and that they might actually speak to that better than their parents:

> It's their life – they know what they need. I know what I need, but my mom might not know exactly to what point of what I need. And if you do it yourself, you're going to get the help you actually need, and not maybe just some other stuff.

Tina credited the information about the IEP process that she received in her resource class with helping her to develop and exercise her self-advocacy skills:

> Ms. Hatlin's class, my junior year, I had a resource class...And the first fifteen minutes, she'd tell us about the IEP, our rights, the rules and all that stuff. I liked it. I mean, cause it's in writing. Like, somebody can't say – you went up to someone and say, "On my last IEP, I asked for a computer, you know, and I wasn't given one." And if they say, "Just do the assignment," I just said, "It's written right in there and everyone signed it."

All of the students appreciated opportunities to learn more about the law and their rights. They felt it was important to learn about their IEP and ways to self-advocate regardless of the degree to which they acted on this knowledge. Brian spoke strongly about wanting to advocate for himself at his IEP meetings, believing that he knew best what he wanted and needed from his program. Like Heather, he believed that, while the teachers were ultimately in control of

program decisions, he saw it as his responsibility to speak up for himself:

> I don't want everybody to make decisions for me, because they don't make the right decisions sometimes. I don't like the ideas that they have, or the things that they come up with – I would rather pick my own classes. They [teachers] remain pretty neutral. They really don't do much at all. They don't really try to help a lot, but they don't really try to control you. They don't stick up for you, they just pick them for you. [They should] ask questions -ask them [students] what they really want to do, and if it's the right decision for them, and make sure the classes are the ones they want to take. They don't do it. They just kind of tell you what you should take, or what they feel is right for you to take.

Devin, a graduating senior who had been in special education since the time he started school, believed that it was the student's responsibility to attend his or her IEP meeting and advocate for what he or she needed and wanted. He saw participation in the IEP meeting as a function of more general involvement in school, and related it to overall motivation:

> It totally depends on how much you want to get involved in your school, I guess. Certain people get more involved in their schooling so, for me, right now, it's pretty much me as far as being in charge. But it depends on what you think of school, I guess. Like how motivated you are to get to where you want to go. It's real important because it's pretty much what you're looking forward to doing in the years to come as far as your school. So you'd want to be in charge, because then you can speak up and tell your teachers or whoever's there what you want to do – not let them make the decisions for you.

Devin did not always participate actively in his IEP meetings but, like other students, he credited his current involvement to a class he took that required students to learn about and participate in their meeting:

> I think it was my sophomore year [that I began getting involved in my IEP] because it was a requirement for class. I really didn't know the purpose or what they were until tenth grade. There was that class I took with Mrs. Woodard. We did a part on the IEP that we filled out on our own. Attending the IEP was part of your grade.

Devin's mother related the fact that Devin had been attending his IEP meetings since he was in middle school. At those earlier meetings, Devin would give his opinion only when asked. As years passed, Devin gained confidence and became a more active advocate in the classroom as well as at the IEP meetings:

> In middle school he started going to the IEPs, and the teachers, instead of talking to me or his dad, would talk to Devin, like "This is our meeting and your parents are just sitting at it." So, they've always made it seem like he was in control of things. He's always been a part of it. So, it's never been, "You're going to do this because I know you can't handle that." It's always, "Well, what do you think, Devin?" They've always asked his opinions. "How was it last year when you took math class? Do you think it would be better if you were in co-taught class again? Or do you want to try it on your own?" And they offer, made it so that he had the choice.
>
> And he seemed to learn real early what his limitations were and what worked well for him. By the time it was his senior year, he pretty much knew what he needed. He didn't have to be told, "I think you would do better here" – he pretty much knew. I think Susan was a lot of it, because Susan really seemed to draw Devin out. She really seemed to include him in the decision-making instead of making them for him. She pushed him to make decisions.

Tracy, like Devin, agreed that it was his responsibility to advocate for what he needed to be successful. He saw this as a time in his life when he should take more control and gain more independence from his parents who were still financially supporting him and making decisions with and for him. Tracy found that the support he got through his resource class helped him to become more vocal in his meetings:

> Well, Mrs.Woodard tries to get us to talk as much as we can. Cause she thinks it's really important to advocate for ourself. Because later on in life, we can't really depend upon our parents to do that, to provide for us, and everything. We're going to have to get our own job, and learn how to balance a checkbook, and all that kind of stuff. I've been trying to do it

> [self-advocate] lately. I've been sheltered for so long, I'm just now getting some responsibility.

Tracy found that attending his IEP meetings provided him with information about what he needed in high school in order to get accepted into college. It helped him to set some concrete goals and understand why it was necessary to take some less desirable classes:

> They're pretty educational about what's going on in the year and my options for next year and options for college and everything. I can follow it [the meeting] pretty easily. [People make me feel that my opinion counts] by asking me like, what kind of college I want to go to, what kind of career, and everything.
>
> I've shared it many times with Mrs. Woodard, and my teachers and everything, that I don't really think that this is going to do anything for me. At least that was last year. Like with algebra, I would be like, "When am I ever going to use it?" That's when I realized that I needed to do that kind of stuff...because there's some stuff that I don't know that I would need to take the ACT and SAT. Like a lot of math stuff like calculus.

Tracy relied upon his teachers to help him make the decisions he did not feel qualified to make alone. Tracy felt comfortable leaving much of the responsibility for schedule development with his teacher, Mrs. Woodard, and making his own decisions regarding his electives:

> Mostly, I just leave that [schedule] up to Mrs. Woodard, because she knows this kind of stuff and knows what credits I need. I do decide what music courses I can take. She'll just give me a little -- just tell me that's a possible class I should take, like for what credits I need -- like English or something, she'll just give me a few examples and I'll pick out which ones I want to take.

Tracy's mother expressed the fact that the family had learned to trust Mrs. Woodard's judgement about what classes would be best for Tracy:

> I think since he has Mrs. Woodard to help him out in school, she has involved him a LOT. She has been such a great help to us and him in high school. He didn't seem to have that much choice earlier. It was pretty

> much he had to take certain courses or whatever, and didn't seem to have much input. But, she has really helped him and us to understand, okay, this is what I think will work for Tracy. This is the kind of class he needs. And then she'll tell him, "This is where I think you need to be placed." And...you know, why I feel that way. And he's pretty much been good about saying, "Okay, that's fine with me." And we feel the same way. We really trust her judgement as far as what she recommends.

Eric believed it was important and helpful to attend his IEP meetings. He also felt that his teachers were valuable resources to him, that they were interested in his input and really listened to him when he discussed what he wanted and needed:

> It's really all about your future, so it's a better idea just to go. They asked me what I would like to do, later, what would I like to do in the future? They really listened to my answers, because they were writing the whole time. Every single time I'd say something, they'd ask me a question, they'd be writing like what I said, like little fragments of it. I kind of see how I'm doing and how I probably will be doing and what I want to do. It's a lot better to go. I put my input when I need it. Cause, usually, they just tell me how I'm doing and what they want me to do, and what do I want to do?

Jim stated that, when he was younger, his mother would not allow him to attend his IEP meetings. He did not wish to relinquish his voice to her and resented the fact that she spoke for him. He felt that she had not represented his wishes accurately. Jim believed students should be more involved:

> My mom, when I was younger, she wouldn't let me come to my IEPs, like in middle school and stuff. And she would just go and not let me go. I think the kids know more what they need than the parents do. And a lot of the parents didn't grow up with the LD situations that we have now, so they don't understand as much as we do.

For Jim, the necessity of attending his IEP meetings was underscored by the fact that his mother no longer saw the need to be involved now that he had moved into high school and his program didn't change from year to year. Jim reported that his case manager also seemed to minimize the importance of his

IEP meetings and was satisfied to have Jim simply bring the paperwork home for his mother to review and sign. Jim stated that he wished he had more of an opportunity to review his program and discuss various options, but he failed to advocate on his own behalf:

> My mom didn't go to mine [IEP meeting] this year or last year. I just kind of talked to the teacher, and he sent me home with the paperwork for her to sign. Last year, I had Mrs. Friedman for my case coordinator, and she was real concerned with what I wanted, and tried to do as much for me as she could. But this year, Mr. Williams is my case coordinator, and he's a lot more laid back about it. He kind of just like blows past it, and he never really even talked to me about it that much. He's like, "This is your IEP – same as last year. I have to get it in before next week, so take it home and have your parents sign it." He didn't really go over it or anything. I would have liked to go over it, but my goals were still the same from last year. And the accommodations that I need are still the same from last year, so there wouldn't be that much of a change.

Despite his desire to have more discussion and input into his IEP, Jim lacked the resources available to some other students that might have made this happen. His need to self-determine collided with the way his teacher's practice ignored a basic principle of IDEA policy, student participation. Unlike some of the other teachers, Jim's caseload teacher had not taken on a strong advocacy role for Jim, nor had he emphasized the importance of Jim's voice to the development of his IEP. Without strong backing, Jim took on a more passive role.

The students and their parents believed that there was value in teaching students to understand their disability and to advocate for themselves. There was disagreement, however, regarding the appropriate age to begin such instruction. Uncertainty prevailed regarding whether or not it was beneficial to begin to work with younger students to understand their learning disability. Students and their

parents believed that, while young students might be confused and unable to self-advocate, it was still better to initiate such instruction at an early age. There was consensus in the group with regard to having students attend their IEP at any age. Jim stated,

> If they can understand the learning disability and understand what they need, they should be able to go to their IEPs and tell them what they need. But before that, you don't really understand anything, so you're not going to be able to tell them anything. Not help out with any information – or anything. It would be nice if they explained it and if they picked up on it and involved them more in it.
>
> When you get into special education programs, you can't really decide for yourself, because you're too young to understand. Like a lot of the programs – it'd be kind of nice if there was a way you could understand it and decide for yourself. So, it would be kind of nice if they could explain it to kids and let them make the decision.

Brian's views aligned with those of Jim. He stated that students should be brought into the process much earlier on, perhaps at the middle school level:

> Students should learn more about the forms and chairing their IEP meetings maybe a little sooner, maybe in middle school. That would probably help – more ability to help kids make their own decisions.

He found that the study skills class he took helped him to learn his way through the maze of IEP forms and procedures and to feel comfortable with the format of the IEP meeting:

> I've just always been able to speak up for myself. I was in charge of what was going on and what I was telling them, but they were going through the forms. I've been to the last three IEPs – this year, last year, and the year before. We are learning how to run our own IEP through study skills- we're learning about that right now. We've learned the first five or six steps to it; you introduce yourself, and you tell what the meeting is about and go through some of the steps and the forms and stuff like that. It's a big help. Otherwise, you wouldn't know what to do at the meeting. Just sit there and wander through the material. You really wouldn't know what was going on or what they were doing. Then I will know how to present the material to the teacher so they will know that you know what's right.

Brian's mother felt that her early involvement as her child's advocate was limited due to her general lack of knowledge about the laws and the process. Information about special education laws and her child's rights, and the process by which to access available programs and services would have been helpful to her in her advocacy role:

> I have a lot better notion (now) about what's going on, what's expected. Some of it is, when you're in elementary school and you're having some of those first IEPs, you're just so bewildered by the process- what's going on with your kid, what the school is going to help you do with your kid. You don't know enough to be enough of an advocate.

Devin, who had been in special education his entire school career, also believed that it would be helpful to involve students at an earlier age. He spoke about his instruction in the Communication for Empowerment class he took in high school:

> I think you have to be a junior to take the class. If possible, I'd look at doing it younger so they know. Maybe in ninth grade year. Yeah, we're all immature little ninth graders, but you'd learn it earlier, and you'd know what to do in situations such as speaking up during classes and (for) accommodations

Heather, the most outspoken of the students, had unequivocal feelings about teaching students as early as possible about their disabilities and involving them in their own IEPs:

> I think it should begin when they first get in the IEP. You start teaching them when they're young. I started in sixth grade, so you start teaching them – see they could have told me about my IEP and how it works. Even though I wasn't going to sit through it, I should still know what's going on about me, cause it's me. You're sitting there, you're telling me how my life is going to be, you know? And I think it's not fair. You should at least give me the satisfaction of knowing how my IEP will go. I think that everyone should come to their IEPs – no matter how old they are. Because they know, by the time they're in fourth grade, what's going on and what their choices are going to be.

Tracy's mother admitted that starting the process earlier with students would help them to be more informed and ready to make responsible choices:

> If they started younger and got used to that, I think they'll be more apt to keep up with it. And I don't know that Tracy didn't hear that earlier on, but I never heard anybody say that until he got to high school – about how you really need to help yourself out. And maybe he wasn't at a point where he could do that , or felt like he could do that, but it really needs to be taught sooner, as far as I'm concerned, because that REALLY helps the ADD student, to be able to succeed, to do well, to do better. I think it's important to be able to ask for it (accommodations) themselves.

Through the interview process, it became evident that student voice and involvement in the decision-making process of the IEP meeting and the development of the educational plan was influenced by many factors. Students varied in their beliefs regarding the importance of their own participation in the meeting. The students' comfort level often depended on their familiarity with their rights and their knowledge and acceptance of their disability. How students viewed their label of "learning disabled" and what that meant to their identity played a role in shaping their involvement. The resources available to them in the form of teacher or parent advocacy also factored into the ways in which students chose to be involved. While many of the students believed that it was important for them to have some role in determining their educational program and class schedule, they were willing to exercise this right by sharing voice with a teacher or parent entrusted with the role of advocate. "Self-determination" then, might mean that the student gives "voice" and advocates for himself through the actual voice of another, trusted individual acting on his behalf.

Summary

"Oh, you have that" – What the journey tells us

The stories the students shared, of their journeys into special education, uncovered the factors that influenced how they navigated their learning experiences, and how they and others mediated through the elements of IDEA policy. The students described their journeys into the system and discussed the various roadblocks and hurdles they faced along their individual routes. Interviews with the students and their parents revealed that the knowledge and understanding they had with regard to their rights under IDEA, and their educational needs specific to their learning disability had a major influence on the ways in which they advocated for and received necessary programs and services.

Their personal journeys began with their entry into special education through the referral process. They evolved through their mediation for a free, appropriate public education in the least restrictive environment. The journeys "ended" with the students' participation in their IEP team meetings. Two schools of theory, labeling theory and self-determination theory provide perspectives that help us to examine and better understand the students' experiences.

The degree to which the students and their parents knew about and understood their rights under IDEA appeared to have a major influence on the ways in which they pursued the programs and services they believed were appropriate to their needs. Several of the parents admitted that, throughout many years of their child's education, they remained unfamiliar with their rights and

uncertain about the process. For some parents, having relatives with disabilities provided them with information about their rights, programs, and services that served as a resource in their negotiations with the school.

The students' understanding and acceptance of their learning disability influenced their degree of involvement in advocating for themselves through the IEP process. Most of the students admitted that, at one point or another in their educational careers, they felt embarrassed and ashamed of being in special education, tired of being "made fun of for something you can't help or change." Several recalled times when, like the poet, Elaine, they "cried for hours on end because you cannot figure out what is wrong with you...." For some, having a label as "handicapped" meant feeling different or "outside" the group of regular education peers. They particularly did not like to recognized as being "special ed," at times refusing to access necessary academic support and services in order to avoid standing out among their classmates. They shared their feelings of longing for friends and teachers "not thinking you are stupid but instead knowing how smart you are and helping you let it show..."

The resources available to the students for support and advocacy seemed to have the most influence on the role they took to access the services they needed. This resource came predominantly in the form of very strong parent and teacher support, encouragement, and longed-for acceptance. Extra help with academic challenges (such as homework, tests, and long written assignments), speaking up on behalf of the student, and holding high expectations were also ways these adults provided support for the students who, like Elaine, the poet,

relied on their help so that they could "...get through life without giving up all hope or struggling alone the entire way." Students with this kind of support were more likely to feel confident in advocating for themselves or placing their trust in another individual, such as a parent or teacher, to voice their concerns and preferences for them. Thus, a student's drive to self-determine did not always necessitate that they speak with their own voice, but could also involve relying on the voice of others to speak on their behalf.

The students and their parents believed that direct instruction with regard to the meaning of their disability, understanding their label, a working knowledge of their learning style, and the accommodations they needed in order to be successful should be provided to students at an early age. This type of instruction, directed at helping the student to develop self-advocacy skills, can be viewed as another resource aimed at supporting the student in developing their self-advocacy skills. Such increased competencies would likely result in a higher degree of self-determination.

The various theories helped to explain and clarify the students' individual experiences. The next chapter discusses the relationship between the theories and the significant findings from the students' stories. Implications of the findings with regard to IDEA policy will also be explored. The relationship of the findings with other research in the field will be discussed. Finally, recommendations for further research and applications of these findings to current practice will be suggested.

Chapter 5

DISCUSSION

This study set out to answer the question, "What factors influence the ways in which high school students with learning disabilities mediate between IDEA policy and district implementation practices, and access special education programs and services through participation in their IEP team meetings?" Nine students with learning disabilities and their parents were asked to reflect on their journey through special education; as they entered the system, experienced the process of referral, evaluation and diagnosis, and negotiated with the district for educational programs and services. The data from these interviews cluster around several themes that define and illuminate the experiences of the individual students throughout their journeys.

This chapter will present an overview of the significant findings of the study grouped around the main themes, discuss the implications of the study with regard to current policy and theory, and consider the findings of the study with relation to existing research. Recommendations for further, related research and implications of the study with regard to professional practice will also be discussed.

Overview of Significant Findings

The stories told by the nine students and their parents demonstrated that they were caught up in many of the same tensions in the field that have been acknowledged by both practitioners and researchers alike. IDEA, and its actualization through implementation, presents both students and educational

practitioners with multiple contradictions that are evident in the students' descriptors of their individual experiences. Responses to interview questions clustered around four main themes that served in various combinations to help explain and illuminate the experiences of the students and their parents as they attempted to mediate access to the programs and services that were their right: (1) their knowledge and understanding of IDEA; (2) their understanding of LD, the meaning of the label, and its acceptance by the students; (3) the students' desire and ability to self-determine, and the meaning of "voice"; and (4) the resources available to students in the form of advocacy, gate-keeping and high expectations. The significant findings around these four themes will be presented here.

Knowledge and understanding of IDEA: What good are "rights" if you don't know how to exercise them?

IDEA provides students and parents with an abundance of rights, but it became apparent that even those students who had been "in the system" for many years were not fully aware of their rights under this law. Although students are guaranteed certain procedural safeguards, it was evident that neither the students nor their parents believed they were adequately informed about their rights under the law. The little knowledge they did receive was gained through gradual, repeated exposure to information, provided by more- or less-informed teachers at annual IEP meetings.

This lack of knowledge pervaded all of the students' experiences as they made their journey through the system. Students could be referred without their

knowledge or understanding for an evaluation, the end result of which could dramatically alter their status and identity to that of a "handicapped" individual. With the diagnosis and label of a "learning disability," students left the realm of "regular education" and entered the domain of "special education."

The IDEA provisions for LRE, FAPE, and participation at the IEP team meetings were vague and confusing for students who lacked necessary knowledge and were ill-prepared to self-advocate. As a result, most of the students and parents lacked a working knowledge of the law that would enable them to exercise their rights. Some students, but not all, were able to gain information through a class, "Communication for Empowerment," created by their special education teachers for that purpose. By offering this class, the teachers were able to prepare the students better for their role as their own advocate. Through this class, students learned the meaning and implications of their label and gained recognition of their particular style of learning. The class provided them with an opportunity to become familiar with the accommodations available to them as special education students and with the structure, format, and paperwork involved with the IEP meeting. Only after they participated in this class did the students believe that they knew enough about the law and their rights to give voice to their wants, needs, and concerns. For these students, this special education class was the key to participation, providing them with the tools they needed for self-advocacy. The need to offer classes like this, that provide students with much more in-depth information about the law, their rights, the

disability and resulting educational needs, at a much earlier point in their careers becomes apparent.

The LD label: Special services at what price?

Being evaluated and labeled as an "individual with a disability" was a painful experience for all the students. For any handicapped student, a label is a reminder of what is "wrong" with them: They are retarded, emotionally impaired, physically handicapped, blind, deaf, or autistic. Unlike these other impairments, a learning disability is usually an "invisible" disability. Until they were labeled, each of the students in the study was just one among other "struggling students" in class. The label served to "certify" one's struggle; it gave notice to the world of one's new status as a member of "special education." It became, in essence, the "Scarlet Letter," the giant "S" on the student's forehead.

All of the students recounted some experiences where being labeled made them feel as if they were "different" from their peers, or were "outsiders." Students were able to accept and come to grips with their label to varying degrees. Some got through periods of teasing and peer alienation and were able to accept their label as a means to access additional help, which they saw as necessary to their educational success. For these students, the label did not consume their identity – it was relegated to a small but necessary role in their life.

Some of the students came to define themselves through their special education label, internalizing it and its implications of limited success. They described periods in their school careers where they allowed their label to define their identity, causing them to "just want to give up." Other students refused to

acknowledge that their label had any impact on their lives. They did not see themselves as handicapped – that was for "other" people. They downplayed its importance and relevance to their education. They refused to disclose to their peers the fact that they had a special education label.

The decision not to self-disclose had several implications. Students put much mental energy into hiding the fact of their disability. For many of the students, accessing special education services was tantamount to acknowledging their label, admitting that they were, in fact, "different." Students were very sensitive to the fact that, by entering certain classrooms, hanging around certain peers, or being seen with certain teachers, they were providing "clues" about their hidden identity. Students became acutely self-conscious of being noticed any time they needed to leave the general education classroom environment to access special education services.

How and where programs and services were delivered, "place," became extremely important. For that very reason, some students refused to access special education services and supports. Others coped with this situation by forming a social group comprised of their special education peers, where they didn't have to worry about standing out. Sensitivity on the part of the teachers to the students' needs to fit in and belong became extremely critical to how and when they accessed available services.

Self-determination: the meaning of "voice"

Perhaps the most significant finding from this study pertained to the students' ability and desire to self-determine. The study began with the hunch

that it was the students' desire, but lack of opportunity to self-determine, that most strongly affected their access to special education programs and services. Through conversations with the students, it became apparent that this hunch was only partly correct. The opportunity for self-determination was provided to the students, in a very limited fashion, by inviting them to attend their IEP team meetings. Although the students did want the opportunity to self-determine, "self-determination" itself meant something different than what was originally thought. What emerged from the data was the finding that, while students chose to be involved at some level in their IEP team meetings, they preferred to turn over their voice to an entrusted individual, most often a parent or teacher, who would speak and advocate on their behalf.

"Self-determination," it turned out, was not something the students chose to take on wholly by themselves. They often felt shy, and lacked the confidence, knowledge, and understanding of the law and procedures that they believed to be necessary to successfully take charge of setting their own course and advocating for themselves. While they clearly wanted to be consulted, students were willing-- they even desired-- to have their parent or teacher be their voice, their spokesperson on the front lines, protecting and defending their educational rights.

Support and advocacy: who will stand by me?

Like the icons of the advertising industry – the State Farm "good neighbor," the Prudential "rock," and Michelin's tires, "coming between you and the road" – the students' parents and teachers served to provide them with

unflagging support and to buffer them from the distress they at times encountered as they mediated access to special education programs and services. In addition to providing support in ways representative of more typical parent involvement, such as helping with homework, conferencing with teachers, and attending school meetings, the parents of the students in this study also supported their children through their unconditional acceptance, encouragement, and high expectations. The matter-of-fact manner in which they addressed their children's concerns regarding their special education status, telling them to "deal with it" and "get over it" helped to set the tone for the students that they could, in fact, be successful despite their learning disability.

Several of the students' families had relatives who also had similar disabilities. A family history of disability provided parents with prior knowledge that included a familiarity with the law, professional jargon, and district implementation practices, which served as a resource to them as they negotiated with the school for special education programs and services for their children. Thus, ironically, previous family involvement with disabilities actually served, indirectly, to benefit some of the students by providing their parents with the "know-how" to mediate the system.

Additionally, teachers also served as a major source of support to the students. At times, they served as "gate-keepers" facilitating student entry into the system by pushing along the referral process. Their knowledge of the students' disabilities and related learning strengths and deficits, and their caring and sensitivity concerning the students' rights to privacy and confidentiality at

times made all the difference with regard to whether or not a student would access available special education support. Time and again, the students reported how their special education teachers would negotiate on their behalf with their general education counterparts for accommodations that would help them to be successful. In this way, special education teachers often served as a buffer against a less sensitive, general education environment, and their classrooms provided a safe haven where students felt free to take risks.

Special education teachers also took responsibility for providing classroom instruction aimed at helping students to understand and accept their learning differences and to advocate for themselves. It was in this classroom arena that students believed they gained knowledge regarding the law and their rights. Classroom instruction in the IEP team meeting process and familiarity with the paperwork was instrumental in increasing students' confidence in their abilities to participate on their own behalf. This is another example of how special education teachers served as a critical resource to students and influenced their ability to access special education programs and services.

Implications of the Study with Regard to Current Policy and Theory

At the heart of this study was the belief that students with learning disabilities wanted greater opportunity to self-determine and to give "voice" to their educational wants and needs. Previous studies, cited in Chapter 2, stressed the importance of self-determination with regard to student motivation, performance, and retention in school. As stated earlier, the findings from this study indicate that, while the students did believe that they should exert more

influence on the decisions that are made on their behalf, many of them were likely to choose to *relinquish* their voice to another, trusted individual who acted on their behalf. The burning question became, "Why?"

This question can best be answered by examining the policy, IDEA, that frames the delivery of special education programs and services to eligible students. IDEA was the outcome of an equal rights ideology, similar to that underlying the Civil Rights Act of 1954, that *all* individuals, regardless of any handicapping condition, be guaranteed a free, appropriate education at public expense. As such, it is a policy born of compassion, protecting students with disabilities from discrimination in the educational arena. What we have learned from the students in this study, however, paints a picture of a policy that is at least as equally alienating as it is compassionate. How school districts go about the business of implementing this federal policy results in practices that are often paradoxical in nature. In order to access the programs and services they need to be successful in school, students must undergo a process that results in their marginalization. The experiences of the student participants in this study bear testimony to the fact that much of what we do in schools in the name of IDEA actually flies in the face of its compassionate intent.

Schools were virtually unprepared when in 1975 the IDEA, then called the Education for all Handicapped Children Act (ECHA), became law. Schools could no longer require parents of children with disabilities to go elsewhere in search of an education for their child. With little warning, schools were required to create programming that adhered to policy guidelines or face losing their federal

funding. The existing culture of the schools was ill equipped to respond to a whole new set of needs created by this policy. School change does not occur quickly, and educators did not have the luxury of time. Their solution was to create the separate, parallel system of "special" education that exists, to various extents, in our schools today.

To understand what led to and sustained a separate system of education for students with disabilities, I relied on my twenty years of professional experience as well as information gathered from the interviews with students and parents to help me examine the multiple factors that acted together to create a "press" on classroom and district-level educators. The passage of IDEA came at a time that also saw an increase in the use of technology and a globalization of the economy. Schools came under fire to produce graduates who could compete in a more global world. American businesses put additional pressure on schools to ensure that students attained competency levels in basic skills. State governments developed core curricula and created related high stakes achievement testing with financial penalties for poor performance.

The pressure on educators to "measure up" continues to intensify. In Michigan, newspapers publish each school's annual MEAP (Michigan Educational Assessment Program) test results on the front page in what is called the "school report card." Given no additional funding, Michigan schools are now mandated to provide summer school programs for any student who cannot read by the end of the third grade. In my professional experience, I have witnessed superintendents, who stand to lose their jobs if their districts don't perform, exert

pressure on their building administrators to improve test scores. I have walked into school buildings during testing season and sensed the tension resulting from this pressure to perform.

The pressure to perform filters down from the state level to the district level, from the district level to the building level, and from the building level to the individual classroom teacher. The stakes for achievement test performance are set higher than ever at a time when teachers face greater diversity within their classrooms than ever before. Today's classrooms are comprised of students who come from widely divergent ethnic, racial and religious backgrounds. They arrive at school with varying levels of readiness skills and speaking a variety of primary languages. Many have been neglected or abused. Many do not have adequate health care or childcare. Thanks to advances in medical care, many children who would not have survived past birth are now surviving, but are coming to school with cognitive, behavioral or motor deficits as a result.

I have spoken with teachers who feel ill prepared to face the daunting challenge of educating such a divergent and needy group of students. They state that they believe they lack the knowledge and skills to teach such a varied group of high needs youngsters, believing, instead, that it takes a "special" teacher with specialized knowledge. Under pressure from administrators and parents to boost student achievement, it seems that many teachers long to narrow their classroom teaching responsibilities to the students "in the middle." Students who are gifted and talented, speak a primary language other than English, or have sustained academic or social-emotional difficulties present more and more of a challenge to

the classroom teacher, who is trying to stretch to meet all these needs. Many teachers may have come to believe that they are no longer the "experts" qualified to teach such children. Is it any wonder, then, that the classroom teacher may look for help from a system that offers to relieve him or her of the "lowest" students?

IDEA, originally intended to *supplement*, not *supplant*, general education, may have become a way "out" for many teachers. It has allowed teachers to discredit themselves as effective teachers of *all* children, and to narrow the field of their learning and expertise. It has, in effect, drawn a "line in the sand," separating special education from general education. Special education has become a totally separate institution, delivered in its own "place," having its own curriculum, paperwork, and professional jargon. This imaginary "line" has become an almost tangible barrier, separating not only students from their peers, but special education teachers from general education teachers as well. The line exists even at the administrative level, where special education administrators have their own funding system, and issues of "ownership" are gray with regard to teacher hiring, evaluation, and staff development. University level teacher training institutions help to perpetuate these distinctions by training general education and special education teachers through totally separate programs, rather than preparing them to teach students in inclusive settings.

Frustrated by an inability to be all things to all children, teachers may look at a referral to special education as a way to secure help for one segment of their classroom population. As the pressure to show results increases, so does the

number of referrals. The "system" has been set up in such a way that it has become almost too easy for teachers to give up, to let general education fail these students so that they can seek the appropriate help for them "elsewhere," and reduce some of their classroom press. The LD student, the "failure," now becomes an "outsider," and someone else's responsibility. The first step into the system, the referral for special education, serves as an indicator to the students that they don't "belong," "I can't teach you," "you don't fit," "something's the matter with you," "you're different" – messages that the students in this study got all too clearly.

A key difference between the Civil Rights Act and the IDEA lies in the identification of those who are considered members of a protected class of citizens. Under the Civil Rights Act, protected citizens are already members of a minority class of people by virtue of their affiliations based on race, religion, or ethnicity. In other words, people automatically come under the protection of the Civil Rights Act simply by virtue of who they are. Under IDEA, however, a person must "apply" for "membership" as part of a protected class of disabled individuals by means of going through the referral, evaluation, and diagnostic process. The resulting label guarantees them the right to protection under this law.

Unlike members of racial, ethnic or religious minorities whose identities have remained stable throughout the course of their lives, students with disabilities are forced to undergo an identity shift, from membership in the mainstream to membership in a minority group, the disabled, in order to access the support they need to succeed in school. It is this shift from the mainstream to

the margins that is the source of much anguish and denial for many of these students and the root of much of their anger and frustration. The students believed that in order to get the help they needed in school, they had to relinquish their membership in the group of "normal" students and affiliate with other, disenfranchised youth who comprise the special education population. We must ask ourselves if forcing students to undergo such a drastic change in status and identity is truly necessary for the provision of educational programs or services.

The way schools are currently implementing IDEA policy creates a dilemma for students. In order to get the help they need, students must first submit to a demoralizing and stigmatizing process which, in turn, may result in their decision not to access services. Steiner (1979) uses the term "evaluative choice" to describe this type of situation, where an individual is free to choose from among several alternatives, none of which they view as viable. Isn't there a better way to provide the protection guaranteed by IDEA that does not force students to choose between accessing the help they need, but suffering stigma, or going without such help - and failing?

For these students, the special education label represented their ticket of admission into minority status and their exit from the group comprised of regular education, non-labeled peers. Labeling theory, expounded upon in Chapter 2, provides a lens for examining this experience as related by the student participants. Findings by Branthwaite (1985) and Mehan et al. (1986), that self-concept is, to a large extent, dependent upon what society and other people tell

us we are, were substantiated by the students in this study. Comments paralleling their assertions, that the label becomes a "social fact" about the child, defining his or her limits and capabilities, also emerged from discussions with the students and their parents. In addition, Langer's findings (1983), regarding the power of the label in influencing individual motivation and performance, were also reflected in students' responses.

Several of the students described seeing themselves as "different" or "outsiders" because of their special education status. Becker (1963) utilized these same terms to describe deviants in his study, but several of the concepts derived from his study also serve to explain how special education students may come to view themselves in this fashion. Becker defined an outsider as a deviant from group rules and, additionally, he explained, "The simplest view of deviance is essentially statistical, defining as deviant anything that varies too widely from the average" (Becker, 1963, p. 4). He continued, adding a medical analogy, "A less simple but much more common view of deviance identifies it as something essentially pathological, revealing the presence of a 'disease'," (p. 5). Becker agreed that neither the statistical nor the medical model provides a totally satisfactory definition. He asserted that there is a central fact about deviance: "it is created by society" (p. 8). Thus, Becker provided us with some insights into how special education students, identified as such through a social mechanism, may come to view themselves as "outsiders" in relation to the larger context of regular education.

Just as important to the students as their label was the *place* in which special education support and services were provided. Students' responses reflected existing tensions in the field regarding what constitutes "least restrictive environment." Nearly every student had a story that gave credence to the arguments put forth by supporters of inclusion, discussed in more detail in Chapter 2. The self-consciousness and shame experienced by the students whenever they had to separate from the general education, "normal" setting to access special education services serves as a powerful argument for provision of special education support within the general education classroom environment. The students' stories give credence to those who advocate that special education should not be thought of as a "place" but rather a continuum of services that can be brought to the student.

Equally as powerful, however, are student testimonies regarding the intimate, supportive environments provided by special education classrooms. Students related feeling part of the group, a sense of belonging, and tacit acceptance among like peers. Such testimonies support the views of Lieberman (1992), Vergason and Anderegg (1992), Zigmond (1995) and others described in Chapter 2 who contend that some students have needs that can only be met in separate, individualized pull-out programs. Thus, the findings from this study provide compelling arguments for both sides of the debate regarding least restrictive environment. They leave us with numerous questions regarding the best way to provide services so as to minimize students' feelings of conspicuousness and marginalization.

These feelings of conspicuousness and marginalization were reduced for some students by the sensitivity of their special education teachers to such issues. Students recounted several incidents where teachers responded very sensitively to the students' hesitancy to be conspicuous among their peers when accessing support. These teachers took pains to respect the students' needs for confidentiality and privacy as they sought to provide them with extra help and accommodations, a fact that was not overlooked but much recognized and appreciated by the students in their comments.

Not only were many of the special education teachers sensitive to their students' feelings, but they often took a personal interest in their activities and lives outside of school, attending sporting events and, in general, just being around to support and encourage them. Several of the students described teachers who were tenacious advocates for them in their dealings with general education classroom teachers who were not always willing to follow accommodations listed in the student's IEP. Many of these students received clear messages from their general education teachers that they did not "belong," or that the accommodations they were provided gave them "unfair" advantages over their peers. For these students, feelings of belonging and acceptance were nurtured by their special education teachers who demonstrated ownership and responsibility for helping them to be successful. Nearly all of the students in the study recounted stories of teachers who were so staunch and reliable in their support that they kept the student going at times when adversity and despair might otherwise have taken over.

The original premise for the study was that special education students want more opportunities in their school program for self-determination and, when denied such opportunities, would be more likely to lose motivation and disengage from their studies. This premise was based on research and theories on self-determination, personal causation, and perceived control by Deci (1995), deCharms (1979), Ryan and Grolnick (1986), and Steiner (1979) described in Chapter 2.

From interviews conducted with the students emerged the findings that while the students did, in fact, want more opportunities to give voice to their educational wants and needs, "giving voice" had a meaning that was previously unanticipated. The students may have felt shy, lacked self-confidence, and were unfamiliar with special education laws and processes. Moreover, they were "worn down" by a system that, in its attempts to provide them with additional support, set about labeling and stigmatizing them, set them apart from their peers, and made them feel as if they did not belong. To these students, "giving voice" meant entrusting another person to advocate on their behalf. Students most often preferred to turn over the role of advocate to their parents or teachers who, they believed, were better able to make critical decisions about their education. They were not, however, willing to give up total control. Students still felt strongly that their voice be heard, but were content to stay in the background, in an advisory capacity. They desired to have their say, to self-determine through "shared voice." This study, then, serves to add to and extend the body of theory regarding "self-determination" in that it provides evidence that, for some people, self-

determination can occur through the voice of another, entrusted individual acting on one's behalf.

Consideration of the Findings with Relation to Existing Research

The findings from this study both support and enhance other, existing research in the field. This study provides a rich, qualitative addition to the quantitative studies that have been conducted on similar topics. Data from this study are presented in the language of the individual students and parents, reflective of their own experiences. From this data, patterns of commonalities have emerged that serve to provide deeper insights into the experiences of students and parents as they mediate access to special education programs and services.

There are several other studies in the field that appear to be somewhat related to the current study. Adelman, along with several other researchers (1992, 1986, and 1983), has been studying the various factors affecting motivation of special education and other, labeled youth, in a variety of educational and clinical settings. Adelman and Taylor came to the conclusion that adolescents were often reluctant to access interventions on their behalf, sometimes even to the point of totally avoiding them when they perceived such interventions as "not beneficial, as potentially harmful, or, more generally, as an unwanted interference" (Adelman and Taylor, 1986; p.91). He attributed this reluctance and avoidance to the lack of opportunity for the student to self-determine, to be involved in the decision-making process regarding treatment programs and interventions.

The 1989 study by Taylor et al., described in Chapter 2, further investigated students' perceived control with regard to educational intervention programs. Two scales were developed for use in the study: the Perceived Importance of Control at School Scale (PICSS) and the Perceived Control at School Scale (PCSS) (Taylor, Adelman, Nelson, Smith, and Phares, 1989). The PICSS was designed to measure just how important students believed it was that they have control over developing and implementing their educational intervention programs. The PCSS measured how much control students perceived they actually had in making such decisions.

In this study, special education students responded to structured questionnaires along a Likert type scale. The findings from this study, discussed in more detail in Chapter 2, revealed that the students desired greater opportunity for self-determination and control with regard to educational decision-making. What the study did not include, however, was a description, in the students' own words, of what they meant by "control" and "self-determination." The present study demonstrated clearly that the term "self-determination" means different things to different people. The "voice" of the student, in exerting control over school decisions, can also include the "voice" of entrusted others.

Margolin (1982) conducted a survey of children's views of their self-determination rights. Her findings, that younger children preferred the protection and nurturance of adults in situations where an improper decision could lead to direct harm, were corroborated by this study of older students with learning disabilities. This leads the researcher to believe that learning disabled youth who

are faced with making important educational decisions may be much like younger children who feel vulnerable to elements beyond their control, and perceive that they need protection in the form of adult intervention on their behalf.

This study most closely relates to research conducted by Murphy (1992) which is described in Chapter 2. Murphy interviewed 49 adults with learning disabilities who had completed either a two- or four-year college or technical training program. The reflections by subjects in his study regarding their personal pain, difficulties, and frustrations that resulted from their diagnosis, label, and special education programming were corroborated by the responses of the younger, high school students in the current study.

Unlike the students in Murphy's study, however, who found their special education classroom placements to be "unhelpful" and, at times, even "aversive," *all* of the students in the present study testified to the help and support they received from their special education placements. When asked what they would choose to do if they were given the choice of whether or not to enter special education, these students responded unanimously that they would, in fact, choose to receive special education support. Despite the pain and stigma of their label and feelings of alienation from their peers, the students in the current study were unequivocal in their belief that the special education support they received was vital to their success in school. What may account for this belief is the way special education teachers provided these students with the unconditional acceptance and positive regard they failed to receive, in any substantive way, in general education.

Recommendations for Further Research

The findings from this study make it clear that further research in related areas is necessary. In particular, additional research needs to be conducted that builds on the findings from this study and studies conducted by Margolin (1982) and Taylor and Adelman (1989) on desire and opportunities for students to self-determine and have control. Further studies will also need to explore the relationship of voice to self-determination in order to gain a better understanding of what students mean when they indicate they want more control.

Student participation in the IEP team meeting beginning no later than age fourteen is mandated by IDEA. It becomes imperative to find ways to actualize participation beyond the passive role students currently play. Findings from the current study indicate that research is needed that continues the work begun by Patricia Phillips (1990) on assessing the effectiveness of an intervention program designed to enhance students' ability to self-advocate. Several of the students in the current study attested that the only way they were able to learn about their disability, their rights under IDEA, and available programs and services was through a class, "Communication for Empowerment," that incorporated such an intervention approach. The students and their parents agreed that students should be taught information about the law and their disability, as well as skills specific to self-advocacy. Further research in this area would be useful in assessing the effectiveness of such programs in improving student self-advocacy and participation in educational decision-making processes. Studies evaluating

links of such programs to increased school performance and retention rates would also be valuable to educators.

Implications of the Study with Regard to Professional Practice

The charge to educators, as made clear by this study, is to reduce the negative impact on students requiring special education services. Educators are faced with the challenge of delivering necessary supports and services without marginalizing students. Students should not have to be faced with "Sophie's choice." They should have ample opportunities to make real, autonomous decisions regarding services that support their personal hopes and dreams and meet their self-assessed needs.

This study holds many implications for professional practice as it relates to the implementation of IDEA within the educational setting. The findings from this study indicate that practitioners need to be sensitive to issues on several fronts:

- as they relate to the identification and labeling of special education students;
- as they develop and implement programs and services related to "place";
- as they encourage students to take on a greater self-advocacy role in the development and implementation of their IEP;
- as they work with parents to ensure the provision of appropriate programs and services; and,
- as they create opportunities for teacher professional development

Given the fact that all of the students admitted to a heightened sensitivity with regard to the labeling process, practitioners are cautioned to review their own attitudes and beliefs about the significance of labels, and not automatically to impute certain traits (laziness, low intelligence, limitations) to students simply because they are "labeled." Before they were evaluated and labeled, students with learning disabilities were similar to other, low achieving students in school. No one knew they were "handicapped." We have seen that without their permission and, in most cases, without their knowledge, students were subjected to an educational evaluation for the purpose of labeling and providing service. This unexpected and undesired status has left many students feeling devalued, discouraged, and angry. Sensitivity by educators to these feelings is critical to student morale and self-esteem.

Attention also needs to be directed toward the cues, both subtle and not so subtle, that practitioners provide to students by their behaviors. Having spent more than a decade teaching special education students at the elementary level, I have witnessed some insensitive behaviors exhibited by my teacher colleagues. On numerous occasions, students in my special education class were turned away from participating in activities in their general education classroom setting simply because no one "remembered" to include them. The birthday party without enough treats, the Christmas party with no grab-bag gift, and the "forgotten" notice and permission slip for the class field trip all attest to the fact that these students were not considered to be true members of the group. They were often viewed as "my" students, "outsiders," to be included as an afterthought, if at all.

In addition to having an increased sensitivity to the students' feelings regarding their label and status as a "special education student," practitioners need to be cognizant of the implications of service delivery with regard to the students' self-esteem. Like the special education teachers in this study who made it a point to be discreet, practitioners should work with students in a way that reflects their respect for maintaining the students' confidentiality and privacy. Whenever possible, special education support should be delivered in the context of the general education classroom so as to reduce the stigma and self-consciousness caused by having to leave in order to access services.

Tensions in the field continue to exist between those who advocate for enhancement of social opportunities for special education students through the provision of services in an inclusive environment and those who maintain the necessity of individualized, small group instruction through a traditional pull-out model. These arguments tend to obscure the real purpose of special education intended by IDEA, which is to increase the students' prospects for self-determination. Mithaug (1996) aptly sums it up when he declares, "The problem with both positions is that neither attaches an ultimate purpose to the particular version of the special education opportunity it advocates" (p. 163). Teachers should leave behind their deficit-driven focus and become concerned with adopting practices that are more student-centered, aimed at helping students to determine their strengths and preferences and set a course for realizing their future dreams.

IDEA was born in an effort to extend equal opportunity for a free, appropriate, public education to all students, regardless of any handicapping condition. The intent was for special education students to become empowered "to enhance their own capacity and to improve their own opportunities for living a self-determined life" (Mithaug, 1996, p. 162). Today there exists a discrepancy between this right and the experiences of special education students with regard to self-determination. For an individual to self-determine, he or she must have both the capacity and the opportunity. Equal opportunity theory explains that "...when either capacity or opportunity to self-determine is diminished or constrained, the experience of self-determination diminishes; when this diminished experience persists, the right to self-determination is abrogated" (Mithaug, 1996, p. 162).

Under IDEA, practitioners are required to invite students, from the age of fourteen on, to participate in their IEP meeting. Often this limited role of IEP participant is the only opportunity students are given to exercise their right to self-determine. It is the responsibility of practitioners to ensure that students are provided many opportunities to take a more active role. Students in this study responded that they did not feel knowledgeable or informed enough to feel comfortable as an active participant. According to the "optimal prospects" principle (Mithaug, p. 161), students require not only the opportunity, but also the "capacity" to self-determine. In addition to providing students with opportunities for self-determination, educators need to provide information and instruction in

the skills necessary to facilitate participation and provide opportunities to practice and role-play a participatory role.

Abery and Stancliffe (1996) advocate for an ecological perspective, which would provide for self-determination instruction that spans the lifetime of the student. They believe that self-determination is a complex process, "more than a collection or composite of skills, knowledge, or beliefs. Rather it is a result of a dynamic interaction between individuals and the environments in which they live" (Abery and Stancliffe, p. 112). The ecological perspective places the personal capacities of individuals within an environmental context. Units of analysis "begin with the person, but also extend outward to the individual's ecosystem... consisting of four different levels, ranging from smallest to largest: (1) Microsystem; (2) Mesosystem; (3) Exosystem; and (4) Macrosystem" (Abery and Stancliffe, p. 114).

In order successfully to prepare individuals to self-determine, instruction and opportunity in this area need to span their lifetime and the environmental contexts within which they live, work and play. Direct instruction and observational learning should take place within the microsystem (the family environment, community, school and work) throughout an individual's lifetime. In addition, interventions and supports from the mesosystem (school-family linkages), the exosystem (external contexts of the educational organization) and the macrosystem (the beliefs and values that are altered by institutional and ideological patterns of society) are also critical to the enhancement of self-determination (Abery and Stancliffe, 1996).

In addition to working better to inform students about the law, their disability, and the available programs and services, practitioners will need to consider their partnership with parents who often serve in the role of advocate for their children. It is clear from this study that parents bring to their advocacy role varying knowledge and resources which directly influence their ability to successfully advocate on their child's behalf. Schools need to address this issue more responsibly by providing opportunities for parents to become better informed about IDEA, their child's learning disability, and available programs and services. It has become obvious that just handing a parent a pamphlet outlining their procedural safeguards does not sufficiently address their needs.

It has been over a quarter of a century since the implementation of IDEA. Yet, there are still teachers who practice as if they have no knowledge of their responsibilities under this law. Time and again we heard from the students and their parents how teachers refused to follow the recommendations in the student's IEP. Students provided accounts of instances where they were denied accommodations that were written right into their plan. Some teachers even stated that they "didn't believe in accommodations"! Others begrudgingly "allowed" students to take advantage of their accommodations, but not before they succeeded in chastising or belittling them with insensitive comments.

It seemed that perhaps the greatest resource to these students were their special education teachers. Students and their parents often cited the caring and sensitivity of these teachers as the reason the students stayed in school. Districts must examine ways in which they can expand upon this resource to students.

They must consider providing professional development opportunities to both general education and special education teachers that increase both their knowledge of special education law *and* their sensitivity to critical issues and student concerns. In addition, districts must continue to investigate ways to attract and keep knowledgeable and dedicated special education teachers at a time when a dire shortage of such teachers prevails.

If educators are to help the students with the greatest academic needs to be comfortable in accessing necessary supports and services, they must find better ways of partnering together, as general and special educators, to break down the barriers that now exist between them. Collaborative efforts should start at the top, with administration working together to develop and implement curriculum and instruction that better serves the needs of a diverse group of students. General and special educators should continue to develop effective models for co-teaching, the method of special education support least stigmatizing to students. Special education teachers must consider how they can serve as a resource to their general education counterparts rather than as a stand-alone support program.

APPENDICES

APPENDIX A

STUDENT INTERVIEW PROTOCOL

I. Appropriate Evaluation: What does the student perceive about his/her experiences with being evaluated for special education eligibility?

A. Tell me about how it was to be referred for special education.

1) When did this occur?

2) Can you describe your school experiences before you were referred?

3) Do you know why you were referred for a special education evaluation?

4) What do you think your parents thought?

5) In what ways were your feelings and opinions taken into account?

B. Tell me about the testing process.

1) How was the testing process explained to you? By whom?

2) Describe your feelings and thoughts about the process.

C. Tell me about having a label of "learning disabled" assigned to you.

1) Do you agree with the diagnosis that you have a learning disability? Why or why not?

2) What does this label mean to you? How would you explain it to others?

3) In what ways do you believe this label affects your life?

4) How do your parents deal with the label? Do you think they treat you any differently because of it?

II. Free Appropriate Public Education: What does the student believe about the appropriateness of his/her education to his/her life goals?

Tell me about the appropriateness of your program to your learning abilities/disabilities.

1) What gets in the way of your being successful in school?
2) How has the school helped you to overcome these barriers?
3) How does your program allow you to get an education that is equal to that of students without disabilities?

III. Individualized Educational Program: What does the student perceive about the individualization of his/her educational program to address his/her own strengths and needs?

A. Tell me about your learning strengths and weaknesses.

1) Can you describe your learning style – the ways you learn best?
2) What do you think you are good at? Do you believe that your special education program builds on these strengths?
3) What do you struggle with? Tell me about the ways in which you believe your special education program supports your weak areas.
4) What do you know about accommodations that can be made to help you be successful? Can you describe some accommodations that help you?

B. Tell me about the IEP meeting.

1) What goes on at these meetings?

2) Are you familiar with the IEP forms? Do you know what is being discussed and written at the IEP meeting?

3) Who is in charge of this meeting? Tell me about your rights; do you know what they are?

IV. Least Restrictive Environment: What does the student perceive about the restrictiveness of his/her individualized educational program?

A. Tell me about when and where you receive help with your work.

1) Where do you go to get help? What do you think about this?

2) What do you feel about your program - is it helping you to succeed in regular classes?

B. Tell me about social things, relationships with friends, time in regular classes.

1) What do you feel about being in classes with your friends – do you get to do this as much as you'd like?

2) How does it make you feel being in special education classes?

3) How do you think students with special needs should get help?

4) If you could have your way, would you be in special ed?

V. Transition: What does the student believe about the ways in which his /her program prepares him/her for post-secondary situations.

A. Tell me about your plans and dreams for after high school.

1) Do you believe you will graduate? Why or why not?

2) What would you like to do? How did you decide this? Who was the biggest influence?

3) What do you think your parents want for you? What are their dreams for you? Do they want you to finish high school? How do you know? Go to college? How do you know?

B. Tell me about how your high school program does or does not help to get you ready for your plans afterwards.

1) Has anyone at school talked with you or your parents about what you would like to do after graduation? What was that like?

2) How have your plans for the future affected your high school program?

3) Is there anything you are learning in high school that you think will be helpful later on?

4) Is there anything that you are doing in high school that may get in the way of what you would like to do later on? Tell me about it.

VI. Parent and Student Participation in Decision Making: What does the student perceive about the extent to which he/she does or does not participate in educational decision making?

A. Tell me about who makes the decisions about school.

1) Do your parents go to your IEP meetings? About how much of the time? Why do you think that is?

2) Do you go to your IEP meetings? Why or why not?

3) How do you feel about taking part in these meetings?

4) Does anyone listen to your feelings about school? Your parents? Teachers? Friends?

B. Tell me about how the school helps you to understand the importance of your involvement in the decisions about your education.

1) Do your teachers talk with you about coming to your IEP meetings and helping to plan your educational program? How does that make you feel?

2) How could your school improve the way it helps you to advocate for yourself? What could teachers do to help you feel more comfortable going to meetings and talking about your learning disability?

3) If you had your way, how would you like to see the schools help students with special learning needs?

VII. Family Involvement

A. Background Info

1) How far did your parents get in school? How do they feel about that? Did either one of your parents have a learning disability? What was school like for them?

2) What types of jobs have your parents had that you know about? Do you think they are happy with their work? How can you tell? Do you think they would have liked to go further along in school? Why?

B. Family Involvement in School Affairs

1) How often do you bring home schoolwork? As often as you should?

2) Who helps you with your homework when you need help?
3) Do you think your parents think homework is important? What makes you say that?
4) Do your parents ever talk with you about your future? Is it important to them that you finish high school? Go to college (or trade school)? How do you know?
5) What would they like to see you become? Their dreams for you?
6) How involved do they get in your schooling: pick your classes (talk it over with you)? Intervene on your behalf to get something you want (a particular class, a particular teacher, avoid a class/teacher)?

APPENDIX B

PARENT INTERVIEW PROTOCOL

I. Parent Education and Background Information

A. School Experiences

1) What was school like for you? Easy /hard?

2) Did you ever have a learning disability? What was it like?

3) How did you get help in school if you needed it?

4) What were you good at in school? Bad at? How did you feel about school?

B. Educational Level

1) How far did you get in school?

2) Do you ever regret not going any further? Why/why not?

3) What were your dreams for yourself? Your life? Have you realized them?

4) Do you feel that you have been limited in what you've been able to do because of school? How so?

II. Parent Involvement in Student's Education

A. Homework

1) Does your child bring home a lot of homework?

2) How do you feel about homework?

3) Who helps your child when he/she needs help?

4) How important do you think it is to get homework done and turned in on time?

B. Educational Decisions

1) Who makes the decisions about your child's education in the family? Why do you think that is?
2) Do you go to your child's IEP meetings? How often? Why? What are they like? What is your role at these meetings?
3) In what ways have you had to intervene in school for your child?

C. Future Plans

1) What are your dreams for your child's future? Does he/she share these dreams?
2) How do you go about helping him/her to reach them?
3) How important is it to you for your child to finish high school? Do you think he/she will finish high school?
4) Do you think he/she feels the same way?

APPENDIX C

IEP TEAM MEETING OBSERVATION PROTOCOL

IEP Team Meeting Observation Protocol

Student Name:_____ Date of Meeting:_____

I. Members Present (Position):

1._____ 2._____

3._____ 4._____

5._____ 6._____

7,_____ 8._____

II. Reason for meeting:

III. Participant Input:

Chair –

Participant #__ –

Participant #__ –

Participant #__ –

Participant #__ –

Participant #__ –

IV. Notes on student's input / participation:

APPENDIX D

APPLICATION FOR APPROVAL OF A PROJECT INVOLVING HUMAN SUBJECTS

APPLICATION FOR INITIAL REVIEW
(and 5 yr. renewal)

APPROVAL OF A PROJECT INVOLVING HUMAN SUBJECTS

University Committee on Research Involving Human Subjects (UCRIHS)
David E. Wright, Ph.D., Chair
246 Administration Building, Michigan State University
East Lansing, MI 48824-1046
PHONE (517) 355-2180 FAX (517) 353-2976
E-Mail - UCRIHS@msu.edu
WEB SITE - http://www.msu.edu/user/ucrihs/

Office Hours: M-F (8:00 A.M.-Noon & 1:00-5:00 P.M.)

DIRECTIONS: Please complete the questions on this application using the instructions and definitions found on the attached sheets.

REQUIRED	
1. Responsible Project Investigator: (MSU Faculty or staff supervisor)	
Name:	Maenette Benham
Social Security #:	
Department:	Educational Administration
College:	Education
Mailing Address:	430 Erickson Hall E. Lansing, MI 48824
Phone	(517) 355-6613
Fax:	(517) 353-6393
Email:	Mbenham@pilot.msu.edu

I accept responsibility for conducting the proposed research in accordance with the protections of human subjects as specified by UCRIHS, including the supervision of faculty and student co-investigators.

SIGN HERE: _____

Note: Without signature, application can not be processed

IF APPLICABLE	
2. Secondary Investigator: (**Students Must Provide Student ID#**)	
Name:	Norma J. Schutzki
Student ID#: or SS#	A20922208
Department:	Educational Administration
College:	Education
Mailing Address:	221 E. Hamlin Street Eaton Rapids, MI 48827
Phone:	(517) 663-5034
Fax:	(517) 627-7811
Email:	Schutn@glps.k12.mi.us

Additional Investigator Information	
3. Name:	
Student ID#: or SS#	
4. Name:	
Student ID#: or SS#	
5. Name:	
Student ID#: or SS#	

UCRIHS Correspondence: Copies of correspondence will be sent to the primary and secondary investigators only. If you would like additional investigators to receive correspondence, please provide further address information on a separate page.

6. Title of Project: Whose IDEA is it, anyway? A look at high school LD student involvement in the IEP process.

7. Have you ever received Preliminary Approval for this project?
No [x] Yes [ ]
If yes, what IRB # was assigned to it? _____

8. Funding (if any) _____
if applicable, MSU Contracts and Grants app. and / or acct. # _____

9. Has this protocol been submitted to the FDA or are there plans to submit it to the FDA? No x] Yes [ ]
If yes, is there an IND #? No [ ] Yes [ ] IND # _____

10. Does this project involve the use of Materials of Human Origin (e.g., human blood or tissue)? No [x] Yes [ ]

11. When would you prefer to begin data collection? mid-September, 2000
Please remember you may not begin data collection without UCRIHS approval.

12. Category (Circle a,b, or c below and specify category for a and b. See instructions pp. 4-7)
a. This proposal is submitted as EXEMPT from full review.
Specify category or categories: _____
b. This proposal is submitted for EXPEDITED review.
Specify category or categories: _____
X c. This proposal is submitted for FULL sub-committee review. X

13. Is this a Public Health Service funded, full review, multi-site project for which MSU is the lead institution? No [x] Yes [ ]
If yes, do the other sites have a Multiple Project Assurance IRB that will also review this project?
[ ] No. Please contact the UCRIHS office for further information about meeting the PHS/NIH/OPRR regulations.
[ ] Yes. Please supply a copy of that approval letter when obtained.

14. Project Description (Abstract): Please limit your response to 200 words.
The purpose of this research is to explore the perceptions of high school students with learning disabilities regarding the efficacy of their special education programming under IDEA (Individuals with Disabilities Education Act). In particular, this study will examine factors that may effect the level and degree of the students' involvement in their individualized educational planning process. This information will be obtained through personal interviews with a sample of LD high school students and their parents. In order to gain a clearer understanding of student input into evaluation and programming decisions, the students' records including evaluation and diagnostic statements and previous IEPs will also be reviewed. Observational data will be collected during students' IEPs to ascertain the extent and nature of

the students' participation in the process, as is the intent of the IDEA.

15. Procedures: Please describe all project activities to be used in collecting data from human subjects. This also includes procedures for collecting materials of human origin and analysis of existing data originally collected from human subjects

Data will be collected through the following activities:

1) **Student interviews**: A sample of approximately 12 high school students with learning disabilities (these students have an IQ within the average range and a discrepancy in their ability to successfully perform in one or more academic areas including: reading, reading comprehension, math, or written expression) will be interviewed concerning their thoughts, feelings and perceptions regarding the evaluation, diagnostic and special education programming aspects of the IDEA (Individuals with Disabilities Education Acts). Interviews will take place outside of regular school hours so as not to interfere with the students' learning. The interview site will be mutually determined by the student and the interviewer, and may include the school, the interviewer's office, the student's home or a neutral site such as a coffee shop. Each interview is expected to take from 1-2 hours and will be conducted using a standardized, open-ended protocol. The focus of the interview will be to elicit from these students their "stories" about dealing with their educational disability. Students will be encouraged to share their opinions about their programs, their ability to be involved, to self-determine, and their perceptions about the amount and types of support they receive.

Interviews will be audiotape-recorded for more accurate reporting of student responses. The tapes will be transcribed and student responses will be analyzed for emergent themes and patterns. Links to existing theories relating to student involvement and/or disengagement in school will be explored. Following analysis, the **tapes will be destroyed**.

2) **Interviews with the parents** of the selected students will also be conducted. A standardized open-ended interview protocol will be followed. The focus of the interview will be: parents' opinions about the type and level of special education support provided to their child; their hopes and dreams for their child; their involvement in their child's educational programming, specifically the IEP process. These interviews will also be audiotaped. Following transcription and analysis, **the tapes will be destroyed**.

3) Notes of observations made during the students' IEP (Individualized Educational Planning) Team meeting. The focus of these observations will be the student's role in the meeting, and his/her involvement and participation in determining the type and level of support he or she is to receive. These observations will be loosely guided by a structured protocol.

4) Notes taken from review of students' files regarding: initial referral information, student evaluation and eligibility information, student's educational program history (where applicable).

The purpose for collecting data from these sources is to confirm student responses to interview questions. That is, data from student files and IEP meetings may serve to triangulate data gathered based on student perceptions.

16. Subject Population: Describe your subject population. (e.g., high school athletes, women over 50 w/breast cancer, small business owners)

The subject population is comprised of:

1) high school students who are eligible to receive special education services according to criteria for learning disabilities. That is, they are of **average intelligence** with a deficit in one or more of the following academic skill areas: reading decoding, reading comprehension, written expression, math calculations, math concepts. These students may also be, **incidentally, but not by design,** minorities, of child-bearing age, low income, or pregnant women. **None of these categories are, however, the intended subjects of study.**
2) Parents of high school students who meet the criteria in #1 above and are living in the same household with the student at the time the research is conducted.
   Parents may also fall into some of the unintended categories listed above: that is, some parents may be of child-bearing age, low income, pregnant women or minorities, but this is not intended.
3) Attendees at the students' IEP team meetings. That may include: the students' special education teacher(s); general education teachers; building administrator; school psychologist, social worker or school counselor.

a. The study population may include (check all categories where subjects may be included **by design or incidentally**):

Minors	[x]
Pregnant Women	[x]
Women of Childbearing Age	[x]
Institutionalized Persons	[ ]
Students	**[x]**
Low Income Persons	[x]
Minorities	[x]
Incompetent Persons (or those with diminished capacity)	[ ]

b. Number of subjects (including controls) 8-12 students and their parents (up to 24). Unknown number of persons attending the IEP team meetings.

c. How will the subjects be recruited? (Attach appropriate number of copies of recruiting advertisement, if any. See p. 13 of UCRIHS instructions)

A letter will be given to each possible subject by his/her special education caseload teacher.

The special education teacher and this researcher will discuss the study with the special education students during a special education resource class, and answer any general questions they may have. A letter will be sent home to the parents of any students interested in participating in the study explaining the study and seeking parental consent to participate.

17. How will the subjects' privacy be protected? (See Instructions p. 8-9.)
Subjects' privacy will be protected as follows:
1) All subjects will be identified only by a randomly assigned number or pseudonyym. None of the notes will bear any names or other identifying information. Although the subjects' identities may be known to the principal investigator and her advisor, the subjects' identities will be kept confidential, and reports of research findings will not permit associating subjects with specific responses or findings.
2) Audiotapes of interviews will be destroyed following transcription and analysis.
3) The district and the school will be assigned pseudonyms; however, it may be possible for someone who is familiar with the district to recognize it by some of the descriptors.
4) Any persons to whom reference is made within the context of a student or parent interview will also be assigned a pseudonym.
5) The identity of participants at the IEP meetings will be protected by assigning pseudonyms.
6) Copies of observational notes, records and transcribed interviews will be kept locked in a secure location (investigator's home office).
7) Only the investigator and her advisor will have access to reading the notes.
8) Subjects will have an opportunity to review a summary of their responses for accuracy following the interview
18. Risks and Benefits for subjects: (See Instructions p. 9.)
a. Risks for the subjects of the study can be assessed as follows:
Talking about their disability may prove to be uncomfortable or upsetting. However, students who are likely to become upset by such discussion will probably choose NOT to participate in this study –an option that will be presented and offered to subjects on an ongoing basis.

Students may believe that what they say may negatively impact their program or their relationships with their teachers. However, no one will have access to any of this information. The nature of the inquiry is such that it will focus on the students' perceptions of their ability to self-determine, to be involved, to plan for life-long goals and the support they believe is necessary to achieve these ends. While it is possible that some discussion may include specifics about supportive/non-supportive staff, this information will be kept totally confidential and is not the focus of the study. As I do not have supervisory responsibilities over staff, these student revelations will not result, even inadvertently, in any repercussions to staff or students.

b. Procedures for protecting against or minimizing potential risks:
For the risk of emotional distress – subjects will be continually reminded that participation is Purely voluntary and that they may withdraw at any point without any "penalty".
For the risk of perceived "retribution" – subjects will be assured of as much anonymity as possible and the confidentiality of reporting the research findings through the use of pseudonyms.

c. The potential benefits to be gained by the individual subjects include:
The feeling of having their opinions, concerns and beliefs held in high regard. Research shows that students enjoy and benefit from empowerment. That is the focus of this study. Another benefit to students will be the improvements and changes made to existing programs as a result of student input. What the students have to say is very important to staff. They routinely survey

special education students to determine what programming "works" and what students believe is not successful. The information gained from the teachers' surveys is typically not as involved and detailed as that which will be gathered through these interviews. We, as a district, should be able to learn a lot from this research about programs and services our students believe will be most supportive and appropriate.

19. Consent Procedures (See Instructions pp. 9-13.)
The informed consent of the students' parents/guardians will be obtained througha letter explaining the study's purpose and activities and the students' and parents'/guardians' rights to voluntary participation and confidentiality.
Before the study commences, the students will be informed of what their participation will involve and of their right to assent or decline to participate. They will be asked if they feel comfortable in discussing with me their perceptions of their special education programs and the development of their special education plan during the IEP conference. They will be asked if they want to exercise their right to decline before any interview or taping takes place, and their permission will be sought regarding access to information from their special education files. Students and their parents/guardians will also be informed of their right to withdraw from the study at any time without penalty.

CHECKLIST: Check off that you have included each of these items. If not applicable, state N/A:

[ ] Completed and signed application

[ ] The correct number of copies of the application and **Instruments** (e.g., surveys, interview questions, questionnaires, etc.) according to the category of review (See instructions pp. 14)

[ ] Consent form (or script for verbal consent), if applicable

[ ] Advertisement, if applicable

[ ] One complete copy of the methods chapter of the research proposal (if available)

APPENDIX E

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS
LETTER OF CONDITIONAL APPROVAL

MICHIGAN STATE
UNIVERSITY

October 3, 2000

To: Maenette K. BENHAM
430 Erickson Hall

From: Ashir Kumar, M.D. Interim Chair, UCRIHS

Subject: Conditional Approval of IRB# 00-555

WHOSE IDEA IS IT, ANYWAY? A LOOK AT HIGH SCHOOL LD STUDENT INVOLVEMENT IN THE IEP PROCESS.

The above named protocol was CONDITIONALLY approved at the UCRIHS committee meeting on: October 2, 2000

A standard approval letter can be issued after the following condition(s) have been met:

Given the small subject population it seems possible that teachers or others in the program will be able to identify the subjects. This information should be added to the consent form.

Please add David Wright's contact information (address & phone number) to the body of the last paragraph of the "IEP Team Meeting. . ." letter. Remove his name and contact information from the signature section of the letter. The IRB Chair is not a co-signer of the letter.

The conditional approval does not allow you to begin data collection or contact human subjects. However, it does mean that the protocol can receive full approval immediately upon the Chair's receipt of the satisfactorily revised forms and will not be delayed until the next meeting of UCRIHS. If you have any questions feel free to call the UCRIHS office.

cc: Norma Schutzki
221 E. Hamlin St.
Eaton Rapids, MI 48827

OFFICE OF
RESEARCH AND GRADUATE STUDIES
University Committee on Research Involving Human Subjects
Michigan State University
246 Administration Building
East Lansing, Michigan
48824-1046
517/355-2180
FAX: 517/353-2976
www.msu.edu/user/ucrihs
E-Mail: ucrihs@msu.edu

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APPENDIX F

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS

LETTER OF APPROVAL

MICHIGAN STATE
UNIVERSITY

October 17, 2000

TO: Maenette K. BENHAM
430 Erickson Hall

RE: **IRB# 00-555** CATEGORY:FULL REVIEW
APPROVAL DATE: October 17, 2000

TITLE: WHOSE IDEA IS IT, ANYWAY? A LOOK AT HIGH SCHOOL LD STUDENT INVOLVEMENT IN THE IEP PROCESS.

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete and I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the **UCRIHS approved this project.**

Conditions set out in 10/3/00 conditional approval letter have been met.

RENEWALS: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Projects continuing beyond one year must be renewed with the green renewal form. A maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for a complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB# and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/CHANGES: Should either of the following arise during the course of the work, notify UCRIHS promptly: 1) problems (unexpected side effects, complaints, etc.) involving human subjects or 2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of further assistance, please contact us at 517 355-2180 or via email: UCRIHS@msu.edu. Please note that all UCRIHS forms are located on the web: http://www.msu.edu/user/ucrihs

Sincerely,

Ashir Kumar, MD
Interim Chair, UCRIHS

AK: bd

cc: Norma Schutzki
221 E. Hamlin St.
Eaton Rapids, MI 48827

OFFICE OF
RESEARCH AND GRADUATE STUDIES

University Committee on Research Involving Human Subjects

Michigan State University
246 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/353-2976
Web: www.msu.edu/user/ucrihs
E-Mail: ucrihs@msu.edu

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APPENDIX G

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS

REQUEST FOR ADDITIONAL APPROVAL

MICHIGAN STATE
UNIVERSITY

Thursday 11 January 2001

TO: UCRIHS
FROM: M. Benham (mbenham@msu.edu)
RE: IRB# 00-555

TITLE: Whose IDEA is it, anyway? A Look at High School LD Student Involvement in the IEP Process
Ph.D. Candidate: Norma Schutzki

Ms. Schutzki's dissertation committee has requested and subsequently approved the additional data collection strategy of interviewing each student's teacher/school psychologist. In some cases, the teacher/school psychologist is the same person. There are no changes in currently approved forms or protocols. We are requesting the review of and approval of the additional cluster of consent forms and interview protocol. We are hopeful that Ms. Schutzki can proceed her teacher interviews in February of 2001.

Please find attached six copies of:

This cover letter.
Student Consent for Teacher/School Psychologist Interview
Parent Consent for Teacher/School Psychologist Interview
Teacher/School Psychologist Interview Consent Form
Special Education Teacher/School Psychologist Interview Protocol

Thank You,

Maenette K.P. Benham
Associate Professor
(Dissertation Chair)

COLLEGE OF
EDUCATION
Department of Educational Administration
Michigan State University
418 Erickson Hall
East Lansing, Michigan
48824-1034

1-517/355-4538
FAX: 1-517/353-6393

HALE Program
423 Erickson Hall
1-517/353-5187

K-12 Program
402 Erickson Hall
1-517/353-8480

Administrative Certification
405 Erickson Hall
1-517/353-5342

Michigan Center for Career & Technical Education
230 Erickson Hall
1-517/353-4397
FAX: 1-517/353-6393

APPENDIX H

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS

LETTER OF REVISION APPROVAL

MICHIGAN STATE
UNIVERSITY

January 18, 2001

TO: Maenette K. BENHAM
430 Erickson Hall

RE: **IRB # 00-555** **CATEGORY:** FULL REVIEW

TITLE: WHOSE IDEA IS IT, ANYWAY? A LOOK AT HIGH SCHOOL LD STUDENT INVOLVEMENT IN THE IEP PROCESS.

ANNUAL APPROVAL DATE: October 17, 2000
REVISION REQUESTED: January 12, 2001
REVISION APPROVAL DATE: **January 17, 2001**

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete and I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the **UCRIHS APPROVED THIS PROJECT'S REVISION.**

This letter notes the addition of interviewing each student's teacher/psychologist and the consent forms.

RENEWALS: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Projects continuing beyond one year must be renewed with the green renewal form. A maximum of four such expedited renewal are possible. Investigators wishing to continue a project beyond that time need to submit it again for a complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB# and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/CHANGES: Should either of the following arise during the course of the work, notify UCRIHS promptly: 1) problems (unexpected side effects, complaints, etc.) involving human subjects or 2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of further assistance, please contact us at 517 355-2180 or via email: UCRIHS@pilot.msu.edu.

Sincerely,

Ashir Kumar, M.D.
Interim Chair, UCRIHS

AK: rj

cc: Norma Schutzki
221 E. Hamlin St.
Eaton Rapids, MI 48827

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APPENDIX I

LETTER REQUESTING PARENT CONSENT

(Date)

Dear Parents,

I am writing to let you know about a research project that I would like to do and to invite you to participate. I am currently the Director of Special Services for the (Name of School District). I am also a doctoral graduate student at Michigan State University. The research I am interested in doing will be useful to me in both of these roles.

As both a Ph.D. student and a Director of Special Services, I am interested in learning more about the special education programs and services provided to high school students with learning disabilities. I want to meet with the students and discuss their involvement in the development and implementation of their special education programs through their IEP (Individualized Educational Plan). The data will be used in the completion of my doctoral dissertation. In the future, the data may be used to improve special education programs and services.

My research plan includes interviewing high school students with learning disabilities to see what they think about the special education referral and evaluation process and the programs and services that have been provided to them under the IDEA (Individuals with Disabilities Education Act). To aid in obtaining the most accurate information, I plan to audiotape these interviews. I will destroy these tapes once they have been transcribed. I also plan to sit in on each student's annual IEP team meeting. During this time I will be taking notes on how the meeting progresses, and the various roles and responsibilities of the participants. In addition, I would like to interview you regarding your perceptions of the support your child has received since becoming eligible for special education and to learn your opinions of the special education programs available to your child. These interviews will also be audiotape-recorded for accuracy. The tapes will be destroyed once the interviews have been transcribed.

In order to learn more about your child's experiences during the referral, evaluation and special education placement process, I would like to review his/her special education file. I will be looking at information on the initial referral form, the evaluation done by the school psychologist, and the MET and IEP forms in the file. I hope to gain an understanding of the difficulties your son or daughter was having in school prior to receiving special education support and the plans developed and implemented by the IEP teams to meet your child's educational needs.

I intend to maintain the strictest confidentiality throughout the course of this study. If I should choose to quote you or your child, your identity will be completely masked by the use of a pseudonym. In all reporting of my findings (doctoral dissertation, journal publications, conference presentations), the name and location of the school and district will also be disguised.

At any time during this study, you and/or your child may choose to withdraw without any penalty or repercussions. In addition, either of you may refuse to answer any question you find objectionable in any way. Throughout the duration of the interview, and prior to the IEP team meeting, I will be checking with you to make certain that you still want to participate. As a way of saying "Thank you" to student participants following the study, I will be presenting your child with a $25 gift certificate to the (Name of Mall).

Thank you very much for considering this request. I hope that both you and your child will participate in this study. Please review and sign the attached consent form if you and your child agree to participate. You can return them to me in the stamped envelope provided. If you have any questions about the nature of this research you may contact Dr. Maenette Benham at the number shown below. If you have questions regarding the rights of subjects and the duties of investigators you may contact Dr. David Wright at the number shown below.

I thank you in advance for your cooperation.

Sincerely,

Norma J. Schutzki
Executive Director of Special Services
(Address of District)
(Telephone #)

Dr. Maenette Benham
Dissertation Committee Chair
Room 430 Erickson Hall
Michigan State University
East Lansing, MI 48824
(517) 355-6613

Dr. David E. Wright, Chair
University Committee on Research Involving Human Subjects
246 Administration Building
Michigan State University
East Lansing, MI 48824-1046
(517) 355-2180

Parental Consent Form

Overview of the study and the consent form process:

I hope to find out from this study some of the reasons that effect how much high school students with learning disabilities become involved in the development and implementation of their individualized educational plans (IEPs). The opinions of the students and their parents about the special education referral, evaluation, and program implementation process will be obtained through interviews. These interviews are expected to last from about 1 to 2 hours. Interviews with students will take place after school hours so as not to disrupt their learning. Information about the student's referral, evaluation, and initial IEP meeting will also be obtained from a review of the student's special education file. Notes from observing the student's annual IEP meeting will also be used as part of the research data.

In addition to getting parental permission in writing, written student assent will also be obtained. Because participation should be completely voluntary, both you and your child can decide that you will or will not be a part of the study. Should you initially choose to participate, you can withdraw from the study at any time without penalty. If you and your child do participate in the study, either of you can choose not to answer any particular interview question.

Confidentiality for all of the data that is collected will be strictly maintained; your name and your child's name will not be used in any reports about this project, and any identifying characteristics of you or your child will be disguised. A pseudonym will be used whenever a reference is made to you or your child, or whenever your comments are quoted. It is possible, however, that given the small subject population, teachers or others in the program may be able to identify subjects through their comments. All interviews will be audiotaped for accuracy; following transcription of the tapes, the tapes will be destroyed. Your child will have an opportunity to review a written summary of the interview for accuracy. Notes from the interviews will be kept in a secure location in the researcher's home office.

Should you and your child choose to participate, I would like to thank your child at the conclusion of the interview by giving him/her a $25 gift certificate to the local mall.

APPENDIX J

PARENT CONSENT FOR STUDENT PARTICIPATION

Parent Consent for Student Participation

Your child is invited to participate in this study. Your child's participation is voluntary, and he or she may decline to participate at any time without penalty. The interview will take between one to two hours to complete. Your child's identity will remain confidential in all reports or publications of the data. It is possible that, despite efforts to maintain anonymity, teachers or others in the program may be able to identify subjects by their comments. Your child will receive a $25 gift certificate to the local mall as a token of appreciation for participating in the study.

Please check below to give permission for your child to participate in this study as indicated:

1) You may interview (and audiotape-record) my child regarding his/her perceptions of the special education referral, evaluation, and program development and implementation process and his/her experiences as a special education student.
   _____yes _____no

2) You may observe and take field notes at my child's IEP meeting.
   _____yes _____no

3) You may review and take notes about the following documents in my child's special education file: referral request for initial evaluation; psychological testing and report of evaluation used for special education placement purposes; all IEPs on file. (Your child's confidentiality will be protected to the maximum extent allowable by law.)

   _____yes _____no

Child's Name (Please Print):_____

Parent/Guardian's Name (Please Print):_____

Parent/Guardian's Signature:_____

Date:_____

APPENDIX K

PARENT CONSENT FOR PARENTAL PARTICIPATION

Parent Consent for Parental Participation

You are invited to participate in this study. Your participation is voluntary and you may decline to participate at any time without penalty. The interview will take between one and two hours to complete. Your identity will remain confidential in all reports or publications of the data. Please sign below indicating your consent to participate in this study.

- - - - - - - - - - - -

I agree to participate in this study. You may interview (and audiotape-record) me about my perceptions of the special education referral, evaluation, and program development and implementation process for my child, and my experiences as a parent of a student receiving special education services.

_____yes _____no

APPENDIX L

STUDENT ASSENT TO PARTICIPATE

Student Assent to Participate

You are invited to participate in this study. Your participation is voluntary and you may decline to participate at any time without penalty. The interview will take between one to two hours to complete. Your identity will remain confidential in all reports or publications of the data. It is possible that, despite efforts to maintain anonymity, teachers or others in the program may be able to identify subjects by their comments. You will receive a $25 gift certificate to the local mall as a token of appreciation for participating in the study.

I agree to participate in this study as follows:

1) You may interview (and audiotape-record) me about my experiences as a special education student.
   ____yes ____no

2) You may observe and take notes at my IEP team meeting.
   ____yes ____no

3) You may review and take notes about the following documents in my special education file: referral request for initial evaluation; psychological testing and report of evaluation used for special education placement purposes; all IEPs on file. (Your confidentiality will be protected to the maximum extent allowable by law.)
   ____yes ____no

Student Name (please print):_____

Student Signature:_____

Date:_____

APPENDIX M

IEP TEAM MEETING OBSERVATION: EXPLANATION OF STUDY AND PARTICIPANT CONSENT

IEP Team Meeting Observation:
Explanation of Study & Participant Consent

I am writing to let you know about a research project that I am doing and to ask your consent to observe and take notes during the IEP meeting for(Name of Student). I am currently the Director of Special Services for the (Name of District) Public Schools. I am also a doctoral graduate student at Michigan State University. The research I am interested in doing will be useful to me in both of these roles.

As both a Ph.D. student and a Director of Special Services, I am interested in learning more about the role of high school students with learning disabilities in the development and implementation of the special education programs and services that are provided to them. The data will be used in the completion of my doctoral dissertation. In the future, the data may be used to improve special education programs and services.

My research plan includes sitting in on the students' IEP team meetings. During this time I will be taking notes on how the meeting progresses and the roles and responsibilities of the various participants.

I intend to maintain the strictest confidentiality throughout the course of this study. If I should choose to quote you in the write-up of my study, your identity will be masked by the use of a pseudonym. In all reporting of my findings (doctoral dissertation, journal publications, conference presentations), the name and location of the school and district will also be disguised. Prior to the IEP team meeting, I will be checking with you and asking you to sign a consent form. It is possible that, despite efforts to maintain anonymity, teachers or others in the program may be able to identify subjects in the study. As a participant in the IEP process, you may refuse to participate in the study. In that event, anything you say or do at the IEP meeting cannot be reported in the findings of the study.

Thank you very much for considering this request. I hope that you will permit me to use any relevant information I might gain for my study from my observation of the IEP meeting. Please review and sign the consent form at the bottom of this page, indicating your consent to have me observe and take notes, which may include your input during the IEP meeting.

If you have any questions about the nature of this research, you may contact Dr. Maenette Benham at the address and number listed below. If you have questions regarding the rights of subjects and the duties of investigators you may contact Dr. David Wright by calling him at (517) 355-2180, or writing him at:

University Committee on Research Involving Human Subjects
246 Administration Building
Michigan State University
East Lansing, MI 48824-1046.

I thank you in advance for your cooperation.

Sincerely,

Norma J. Schutzki
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CONSENT FORM

I understand that, by signing this form, I am giving my consent to have my input at the IEP meeting for (Student name) used for the research study being conducted on the involvement of high school students with learning disabilities in the development and implementation of their individualized educational plans.

I also understand that every effort will be made to protect my confidentiality to the maximum extent allowable by law and that, should my comments be quoted in the research findings, a pseudonym will be used. I also understand that the name and location of the school and the school district will be masked as much as possible.

Understanding all of this, I freely give my consent to have the researcher observe at the IEP meeting and take notes that may include my verbal comments.

Name (please print):_____

Signature:_____

Date:_____

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