A Case Analysis of Three Middle-School Boys Who Have Down Syndrome and Have Been in Regular Education Classes Since Preschool

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A CASE ANALYSIS OF THREE MIDDLE-SCHOOL BOYS WHO HAVE DOWN SYNDROME AND HAVE BEEN IN REGULAR EDUCATION CLASSES SINCE PRESCHOOL

A Dissertation

Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Philosophy

by

Eileen Frances Luddy

June 2002
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July 18, 2002

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ABSTRACT

A CASE ANALYSIS OF THREE MIDDLE-SCHOOL BOYS WHO HAVE DOWN SYNDROME AND HAVE BEEN IN REGULAR EDUCATION CLASSES SINCE PRESCHOOL

by

Eileen Frances Luddy

Chair: James A. Tucker
ABSTRACT OF GRADUATE STUDENT RESEARCH

Dissertation

Andrews University
School of Education

Title: A CASE ANALYSIS OF THREE MIDDLE-SCHOOL BOYS WHO HAVE DOWN SYNDROME AND HAVE BEEN IN REGULAR EDUCATION CLASSES SINCE PRESCHOOL

Name of researcher: Eileen Frances Luddy

Name and degree of faculty chair: James A. Tucker, Ph.D.

Date completed: June 2002

This study investigated the experiences of three middle-school boys who have Down syndrome and have always attended regular education classes.

Despite the existence of policies and initiatives in support of inclusive education, research on the implementation of inclusive practices in middle schools is sparse.

This study is organized in nine chapters. A review of literature revealed that significant research conducted during the past decade supports the practice of including students with disabilities in regular education and the benefits of inclusion outweigh the benefits of separate instruction.
A case study approach investigated the phenomenon covering contextual conditions surrounding the experiences of the three students. The parents of the three students participated in a focus group interview. The teams that support the students were interviewed. Three to four friends of each boy were interviewed. Direct observations occurred in each school. The observations were videotaped, transcribed, and analyzed. Documents from the students educational records, including the IEP and work samples were analyzed.

Each student is presented in a profile. The students teams are profiled, and their educational programs are discussed. Triangulation of the data and analysis of the transcripts culminate in a representation of each student in “a day in the life of…” story. A cross-case analysis compared the students Individualized Educational Plans and overall educational services.

Patterns of themes emerged in the early stages of the study and transcended the three cases. The conclusion identifies components to successful inclusion. The effect the students’ had on others and the limitations of labeling are discussed.

The themes of satisfaction and relationships emerged and were paramount in the students successes. Learning was evident throughout the study. The learning that occurred, not only for the students, but for all of the members of their teams, contributed to the quality of this study.
ACKNOWLEDGMENTS

It took a village to make this happen. There are many people who have given me their time, energy, and prayers during my journey in the Leadership program. I must first thank my husband Ed and son Chet. Their love, patience, and endless encouragement have allowed me to complete the program.

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To Dr. Beverly Rainforth, my long-time friend and heroine, whose leadership in collaboration and knowledge of inclusion gave me direction to pursue this project.

To my siblings and their partners, for the unconditional love and joy that we share in each other’s lives. They have always been there for me.

The network of first cousins in my life is second to none. I know of no group that can match the love and connections that we enjoy.

My wonderful circle of friends, associates, and colleagues from the northeast regional group have all contributed significantly to my learning. I appreciate every one of them.
Finally, a sincere thank-you to the three boys, their families, and the school teams who participated in this study. Without their cooperation and participation, this would not have been possible. I will always be indebted to them.

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CHAPTER 1

INTRODUCTION

*There is only one child in the world and that child’s name is ALL children.*
—Carl Sandberg

**Background of the Problem**

The delivery of educational services to students who are labeled mentally retarded is in the process of unprecedented change (York & Tundidor, 1995). The long history of segregation and exclusion experienced by children with this label is coming to a close. Before 1975, children with significant disabilities were not allowed access to public schools (Ferguson, 2000). Since Public Law 94-142 was passed, public school districts were required to create educational programs for all students, regardless of their disabilities. Specifically, the law states:

That to the maximum extent appropriate, handicapped children, including those children in public and private institutions or other care facilities, are educated with children who are not handicapped, and that special education classes, separate schooling, or removal of handicapped children from the regular education environments occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aides and services cannot be achieved satisfactorily.
The movement to include students with severe disabilities as full-time members of general education classrooms has been based, for the most part, on constitutional grounds (i.e., The Fourteenth Amendment), legal precedents (Holland v. Sacramento Board of Education, 1994; Brown v. Board of Education, 1954; Daniel R.R. v. State Board of Education, 1989; Oberti v. Board of Education, 1993; Ronker v. Walter, 1983) and ethical considerations (Kunc, 1992; Stainback, Stainback, & Jackson, 1992; Wolfensberger, 1972). There is a growing body of literature that supports the full inclusion of students who are considered severely disabled (Lipsky & Gartner, 1989; Stainback & Stainback, 1992; Stainback, Stainback, & Forest, 1990; Villa, Thousand, Stainback, & Stainback, 1992), and a clear mandate exists for students with disabilities to have the same opportunities as their non-disabled peers (Strully & Strully, 1985, 1989).

Court cases in the past decade have supported the concept of inclusive education and have made forced segregation illegal. Two of these cases, Holland v. Sacramento Unified School District (Court of Appeals decision rendered in 1994) and the Oberti v. Clementon School District (1993; Court of Appeals decision rendered May 1993) have confirmed the rights of children with mental retardation access to regular education classrooms. Both of these cases have asked the courts to clarify school districts' responsibility with regard to inclusive education for children with disabilities, and in both cases, the courts have required school districts to create inclusive educational opportunities for these students (Holland and Oberti).

U.S. Circuit Court Judge Edward R. Becker ordered the inclusion of Rafael Oberti and wrote:
We construe IDEA's mainstreaming requirements to prohibit a school from placing a child with disabilities outside of a regular classroom if education of the child in the regular classroom, with supplementary aids and support services, can be achieved satisfactorily.

The emergence of full inclusion as a conceptual framework for educating children with disabilities has generated considerable attention. Several important initiatives regarding education of children with and without disabilities have been observed nationally. Expanded federal funding opportunities and the National Association of State Boards of Education report (1992) outlined specific directives for promoting inclusive education. Originally, inclusive education emerged from ethical issues and civil rights (Brown, et al., 1989; Lipsky & Gartner, 1989; Stainback, et al., 1990).

Current discussions of inclusive education have allegedly moved beyond the philosophical and ethical questions and have focused on ways to support children with disabilities in general education settings (Giangreco & Putnam, 1991; Salisbury, Palombaro, & Hollowood, 1993; Stainback & Stainback, 1992). Bogdan and Biklen (1992) point out that successful inclusive schools consider how to include children with disabilities in their home school instead of asking why.

The underlying value of inclusive education was that all children, regardless of their abilities, should be welcomed members of their classroom, school, and community. A significant amount of research had been done on supporting individual students with disabilities in general education classes (Brown et al., 1989; Cushing & Kennedy, 1997; Kleinert, Kearns, & Kennedy, 1997; Ryndak & Alper, 1996, Sax, Fisher, & Pumpsian, 1996). The resulting database indicates that it is more than possible to provide students with disabilities access to the best available educational practices and to demonstrate

**Statement of the Problem**

Despite the existence of policy statements and other initiatives in support of inclusive education for students with disabilities, there has been a sharp contrast between the optimism emerging from national discussion of inclusion and what is occurring regionally. The recent re-authorization of The Individuals with Disabilities Education Act, IDEA (PL 105-17) includes general provisions that encourage the placement of students with disabilities in inclusive classrooms (Turnbull & Turnbull, 2001). Further support for including children with mental retardation in regular classes came from the U.S. Office of Education, which recently adopted policies encouraging inclusion of all students in the mainstream wherever and whenever possible.

Why, then, are the majority of students with mental retardation, or intellectual disabilities, still educated in segregated or self-contained special-education classes? Lack of information is a common barrier to successful inclusive education. Most general educators and many special educators are unfamiliar with effective strategies for educating students with disabilities outside of separate special-education classrooms. Many teachers are fearful of having students with mental retardation in their classrooms because they have not had previous experience or seen successful inclusive education in practice. In addition, many people are unaware that proposed reforms for general education represent the same kinds of instructional approaches that support successful inclusion of students with disabilities.
Negative attitudes toward students with mental retardation serve to define and limit expectations for children with disabilities and continue to influence special education practices and placement patterns. Although the reasons are multifaceted, the consequences of these attitudes and practices are found in the limited outcomes for students served in the separate special-education systems (Lipsky & Gartner, 1997). Stereotypes and other negative perceptions held by ordinary citizens are often the most significant "handicap" for students with mental retardation (Haring, 1996; Harris & Associates, 1994; Voeltz, 1982). Schwartz and Baer (1991) define "handicap" as (1) the challenge associated with permanent disability and (2) the barriers imposed by society. Haring (1991) posited "that disability is more an attitude held by professionals and non disabled people than it is a property of defining characteristic of the person with disabilities" (p. 97).

The research evidence on the subject of inclusive education maintains that the attitudes of students without disabilities do not regress, but actually improve as schools implement inclusive education practices (Amado, 1993; Siegel & Jausovec, 1994; Stainback & Stainback, 1992). Even so, attitudinal barriers were often cited as a reason not to integrate students with mental retardation in typical environments (Harris & Associates, 1994; Shaver, Curtis, Jesunathadas, & Strong, 1987).

Differences in professional judgment and local practices have also influenced the variations in classification and placement decisions for children with mental retardation. Such variations suggest that the federal monitoring efforts have not proven effective. The ARC (formerly Association for Retarded Citizens) conducted annual studies of the placement of students with mental retardation (Davis, 1994, 1995). The organization's
annual report stated that “on the anniversary of the Individuals with Disabilities Education Act [for children with mental retardation] ... placement in segregated educational environments continues to be the rule of the land” (1995, p. i).

**Purpose of the Study**

There is only an emerging literature providing evidence that full-time membership in general education classes offers a more optimal learning and social environment than special class placement (Hunt & Farron-Davis, 1992; Rainforth, 1992; Schnorr, 1990). If policy, placement decisions, and program design are to be based, at least in part, on sound empirical evidence, a fuller understanding of the outcomes of integration is urgently needed.

The main purpose of this study was to examine the educational programs of three boys in middle school who have Down syndrome (labeled mentally retarded) and have been in regular education classes since preschool. This qualitative case analysis compares their educational experiences and the perceptions of their parents, school team members, and friends. A review of literature did not yield any studies that addressed the combination of the above conditions. Accordingly, the following questions are examined.

**The Research Questions**

1. What constitutes a successful program of inclusive education for students in middle school who have Down syndrome?
2. In what ways has their participation influenced others?

**Overview of Methodology**

This case study examines the phenomenon of inclusive education for three boys in middle school. Each student was observed for approximately 5 hours. Each team was interviewed, using a graphics approach (Mount & Zwernik, 1988). Friends of the three boys were identified by the parents and school personnel and subsequently interviewed. The three sets of parents participated in a focus group. I corroborated the data generated from the observations, the team interviews, the friends' interviews, the focus group, the students' Individualized Education Plans (IEPs), and the students' work samples. The students' IEPs and their work samples were analyzed in the context of their relationship to classroom instruction and the process by which the documents were generated.

The observations, interviews, focus group, and friends' interviews were all videotaped. The focus group was also audiotaped. The videotapes provided me with much richer information than was merely duplicated by audiotapes. Audiotapes, however, were used to process information learned subsequent to each observation, interview, and data collection phase in this study. Talking into an audio recorder added details to the data observed and recorded during data collection. A journal and field notes were maintained throughout the study. Correspondence via the U.S. Postal Service, electronic mail, and telephone communication with participants in the study provided me with opportunities to plan, clarify, and confirm information with the participants.

An independent observer recorded responses and impressions during the focus group and independent coders recorded codes and themes during the analysis phase of
this study. Both of these efforts contributed to the overall reliability of this study. The
data gathered on each student are organized into chapters that include background
information about each boy to provide the reader with information about their family,
early experiences, and educational placements. Each of the teams is then described,
identifying the roles they play and how they function as a team. The students'
educational programs are described in detail, using best practices, defined later in this
chapter, as a guide. The observations, relationships, and work samples are described. I
then highlighted the unique aspects of each student's experiences as a student in middle
school. Themes and impressions are described for each student.

A cross-case analysis (Merriam, 1998) compares each of the educational
programs and the teams, highlighting their similarities and differences, using best
practices as a guide. The conclusions I drew from the data sources are presented using
themes that emerged during this study. The last chapter in this study describes who I am
and where the passion and persistence to complete this study originated.

Definitions of Terms

Inclusion

Inclusion was defined as a movement that sought to create schools and other
social institutions based on meeting the needs of all learners as well as respecting and
learning from each other's differences (Salend, 1998). Although the inclusion movement
had focused on individuals with disabilities, as it has emerged, it has altered the
philosophy for educating all students (Ferguson, 2000).

Inclusive education is an attitude—a value and belief system. The beliefs are
based on the premise that all children, regardless of their abilities or disabilities, should
be a member of all regular education opportunities. Once adopted by a school district, it should drive all decisions and actions by those who have adopted it. The word *include* implies being a part of something, being embraced into the whole. *Exclude*, the antonym of include, means to keep out, to bar, or to expel. If a student is considered fully *included*, the assumption is that the student spends *all* of his or her time with non-disabled students in the regular education classes. Some school personnel use the word inclusion to refer to opportunities for students to participate in *some* of the regular education classes. Some school systems have developed "inclusion opportunities," or programs, that allow children with disabilities to participate in activities with students who are not identified as disabled. Hunt, Alwell, Farron-Davis, and Goetz (1996) concluded from their study that inclusive placements promoted and maintained interactive partnerships among students with and without severe disabilities.

For this study, inclusion is defined as an educational program that provides the students (from this study) access to and participation in the general education activities that are available to their (same-age) typical peers in middle school. Inclusion requires the students to be physically present in the integrated settings (that is, with students who do not have disabilities), and to receive instruction in those settings. I assumed that the students selected for this study had access to the same general education activities as their peers, and *feel* like they are part of the activities and are not just present.

**Mental Retardation**

*Mental retardation* refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning (i.e., IQ), existing
concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. The following four assumptions are essential to the application of the definition:

1. Valid assessment considers cultural and linguistic diversity as well as differences in communication and behavioral factors;
2. The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual’s age peers and is indexed to the individualized needs for supports;
3. Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities; and
4. With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve. (Luckasson, et al., 1992, p. 1)

Based on the 1990 census, an estimated 6.2 to 7.5 million people have mental retardation. It is 10 times more common than cerebral palsy and 28 times more prevalent than tube-related birth defects such as spina bifida. It affects 25 times as many people as blindness (Batshaw, 1997). Mental retardation cuts across the lines of racial, ethnic, educational, social, and economic backgrounds. It can occur in any family. One out of 10 American families is directly affected by mental retardation.

Mental retardation can be caused by any condition which impairs development of the brain before birth, during birth, or in the childhood years. Several hundred causes have been discovered, but in about one third of the people affected, the cause remains unknown. The three major causes of mental retardation are Down syndrome, fetal alcohol syndrome, and fragile X syndrome (Peuschel, 1990).
Down Syndrome

The selection of students with Down syndrome for this study was based on the tenet that children who have Down syndrome usually have intellectual limitations and visible characteristics that contribute to the perception that a student has mental retardation, and are consequently labeled mentally retarded. The first description of a child who presumably had Down syndrome was provided by Jean Esquirol in 1838. Shortly thereafter, in 1846, Edouard Sequin described a patient with features suggestive of Down syndrome, a condition he called “furfuraceous idiocy.” In 1866, John Langdon Down published a paper describing some of the characteristics of the syndrome, including rounder and smaller head size, a flattened facial appearance, slanted eyes, and shorter fingers and toes. The syndrome now bears his name. Down described some of the classical features of this condition and thus distinguished these children from others with intellectual disabilities (Peuschel, 1990).

IDEA

The Individuals with Disabilities Education Act (IDEA) is a federal law mandating that all children with disabilities have available to them a free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living (P.L. 105-17, 1997). It provides funds to assist states in the education of students with disabilities and requires that states ensure that the rights of children with disabilities and their parents are protected. IDEA also assists states in providing early-intervention services for infants and toddlers with disabilities and their families.
Children ages 3 through 21 who need special education and related services because of a disabling condition are eligible for such services under the provision of IDEA. A child with a disability is defined as one with mental retardation; a hearing impairment or deafness; a speech or language impairment; a visual impairment, including blindness; emotional disturbance; an orthopedic impairment; autism; traumatic brain injury; any other health impairments; a specific learning disability; deaf-blindness or multiple disabilities (IDEA, 1997).

The public education agency must conduct an evaluation to determine whether the child has a disability and what the child's educational needs are. To do this, the education agency must take reasonable measures to obtain the parents' consent. The school district must use testing materials free from racial or cultural bias and be presented in the child's native language or means of communication. Trained and knowledgeable personnel must administer the tests. A team of qualified professionals and the parents of the child determine if the child is eligible for services.

Best Practices

The best practices for educating children with severe disabilities and the characteristics of a quality education program were developed by Williams, Fox, Thousand, and Fox (1990). These best practices are based on a premise that the education of students with severe disabilities requires a team of professionals who work in a collaborative fashion, providing structure and opportunities in educational environments where children without disabilities receive instruction. There are nine
practices that are used in this study as a basis for discussing the educational services for the boys selected for the study. They include: (1) Age-appropriate placement in local public schools, (2) Integrated delivery of services, (3) Social integration, (4) Transition planning, (5) Community-based training, (6) Curricular expectations, (7) Systematic data-based instruction, (8) Home-school partnership, and (9) Systematic program evaluation.

Middle School

Adolescence is a challenging time in every person’s life, and perhaps more so for individuals with special needs. It is a stage when young people are attempting to free themselves from the role of a child, while still not yet fully equipped to assume the responsibilities of a mature adult. Middle schools are typically organized to educate students ranging in ages from 11 to 14, who are in Grades 6, 7, and 8. “Most adolescents attend massive, impersonal schools, learn from unconnected and seemingly irrelevant curriculum, know well and trust few adults in the schools, and lack access to adequate supports” (Carnegie Council on Adolescent Development, 1989, p. 13). This statement has been an accurate summary of school life for middle-school students.

Counts tallied in the mid-1990s show that there are 13,543 middle schools in the United States, serving 8,830,036 students with an average of 652 students per school (Irvin, 1997; McEwin, Dickinson, & Jenkins, 1995). The selection of students in middle school for this study was based on the premise that inclusion in such typical learning environments would yield an understanding about the nature of each boy’s educational experience and the effect that his enrollment in middle school has had on others.
Triangulation

_Triangulation_ is one of six basic strategies used by an investigator to enhance internal validity in a study (Merriam, 1998). Foreman (1948) recommended the use of multiple investigators, multiple sources of data, and/or multiple methods to confirm emerging findings. In a more recent article, Mathison (1988) suggested shifting the notion away from "a technological solution for ensuring validity" and instead relying on a "holistic understanding" of the situation to construct "plausible explanations about the phenomenon being studied" (p. 17).

In this study, I collected data from a variety of sources, which included a focus group with the parents of the three boys, interviews with the professional and para-professional members of the educational teams, and interviews with classmates of the boys. I also observed each of the boys for a full day of school and reviewed documents from their educational files. These data sources helped me to make sense of the experiences that the participants have had, which led me to a holistic understanding of the phenomenon in this study. This approach strengthens reliability and internal validity.

Organization of the Study

Following this introductory chapter, the study is organized in the following manner:

Chapter 2 provides an overview of the literature that has evolved regarding inclusive education. This chapter discusses the research that contributed to the
development of programs and practices that were validated and deemed successful. The barriers to implementing inclusive practices are identified along with the limitations of current assessment tools. The issues surrounding the definitions of mental retardation and intelligence are discussed. The role of the teacher and the problems with training are presented, and the impact that students with disabilities have on their non-disabled peers is presented.

Chapter 3 focuses on the general methodology that I selected for this study. A qualitative approach was chosen to provide "thick, rich, descriptions" and understand the participants' perspectives (Bogdan & Biklin, 1992). The purposeful sampling procedure used to select the participants for the study is described. The data collection procedures are delineated. All of the interviews and observations in this study were videotaped to enhance validity and reliability. Information regarding how this was accomplished is described.

Chapters 4, 5, and 6 provide the reader with descriptive information about each boy, their educational experiences, and an interpretation that I wrote after collecting the data, analyzing it and sharing my interpretations with the participants in this study. These three chapters are organized in the same fashion. The first subheading of the chapter is titled "Who is (student's name)?" This provides the reader with background information about the boys' families, their early experiences in life, and relevant information that provides the reader with an understanding of who each boy is.

The "Team" section provides the reader with information about the people who supported each student. The team members who participated in the semi-structured
interviews are described along with information about how they operated as a group charged with implementing the students' educational plans.

The "Educational Program" section describes each boy's Individual Education Program plan. Consideration of best practices, developed by Williams, Fox, Thousand, and Fox (1990), is used as a guide in analyzing the educational services for each student. The students' work samples, observations, and social relationships (friendships) are taken into consideration during this phase of the study and are described.

These three chapters include stories titled "A Day in the Life of (student's name)." They were created to provide the reader with a rich description and composite understanding of what a day in the life of each boy might be like. The sources of data used to write the stories came from a combination of the interviews, stories shared by parents, team members, and friends, along with my observations and the documents that were analyzed. Each chapter ends with a summary of themes and impressions.

Chapter 7 contains the cross-case analysis of this study. The introduction describes the methods for analyzing the three cases, which led to the categories and themes. The educational teams were compared, specifically identifying their similarities and differences. The educational programs were compared, using the considerations for best practices as the basis for comparison. All of the data sources for each student have been used to complete this chapter.

Chapter 8 describes the conclusions of the study. The introduction reviews the purpose of the study and the methods that were used to complete it. The first research question is answered using the consideration of best practices as a basis for discussing the outcomes. The various components of a successful inclusive education program are
described, with examples from the three cases used to enhance understanding. The second research question was answered using the themes that emerged throughout the study, namely satisfaction, relationships, and learning. Each of the themes is identified and described in detail.

Chapter 9, the rest of the story, provides the reader with insight into who I am. This chapter allows the reader to understand why I have the passion and persistence to complete this study.

**Limitations**

Selection, geography, and mortality pose three major threats to the validity of this study (Gall, Borg, & Gall, 1996). A threat is created by the sampling strategy. Based on the criteria I developed, there are few children in the state who have mental retardation and have been in regular education classes for all of their school years. This study is conducted in a small state, in three public middle schools. This threat is somewhat reduced by the variety of communities where the three students live, including rural and suburban settings. The number of students in the study and the fact that it was conducted only in one state is limiting. This study is also limited by the age range of the students, possibly limiting generalization to other age groups.

Possible threats due to mortality or “human limitations” exist due to the personal or professional investment the participants in this study have in each boy’s educational program. This was controlled by selecting three cases for comparison. Another threat to this study lies in the personal and professional experiences, feelings, or beliefs that I hold relevant to students with mental retardation and the delivery of special education.
services. I believe that students with mental retardation are better served in inclusive settings in their neighborhood schools. Strategies used to control the effects of my biases on my conclusions included (1) my decision to not discuss my professional experiences or beliefs with the participants prior to data collection, and (2) use of independent observers and reliability coders to provide independent opinions to temper my biases. Finally, "case studies can oversimplify or over exaggerate a situation, leading the reader to erroneous conclusions about the actual state of affairs" (Merriam, 1998, p. 42). I purposefully remained aware of these limitations throughout this study.

**Delimitations**

The students, parents, school teams, and friends who participated in this study were selected based on criteria I established and their willingness to allow me into their lives. The number of hours that the students were observed and the amount of time committed to this nonfunded project were based on the belief that I could complete this study as an individual researcher who possesses great interest but limited time. The fact that the study was conducted in one state was based on manageable proximity.

**Contribution of the Research**

This study validates a variety of inclusive education practices. In the field of applied behavior analysis, there has been long-standing concern about why innovations—clearly "validated" empirically in published research—were not readily adopted by
practitioners (Meyer, 1991). Wolf (1978) directed our attention to what he called social validity. He argued that behavioral interventions might not be used by the professional community for whom they were intended unless, somewhere in the research process, we considered the opinions, perspectives, and capabilities of those constituencies. The consumers of our research need to be asked what their perceptions or thoughts are. This study provided participants an opportunity to share their thoughts and experiences.

This study contributes to the body of literature on inclusive education and the design of educational services for children with intellectual learning differences. This study addresses a need to describe successful educational programs and the strategies that make them work. The information gained in this study may help professionals consider how to include children with intellectual disabilities in their neighborhood schools. It may also help to dismantle some barriers to inclusion within schools.
CHAPTER 2

REVIEW OF RELATED LITERATURE

I rejoice in the dawn of a better understanding of such children, for the public attitude until now has been a sorely mistaken one.

—Pearl S. Buck

Introduction

The literature on delivering inclusive education for students with severe disabilities is growing (Buswell, Schaffner, & Seyler, 1999; Downing, 1996; Jorgensen, 1998; Ryndak & Alper, 1996; Sapon-Shevin, 1999; Siegel-Causey & Allinder, 1998; York-Barr, 1996). There is a growing body of research examining (1) whether integrated educational placements were more beneficial than restrictive placements (Brinker & Thorpe, 1984; Carlberg & Kavale, 1980; Ryndak, Downing, Jacqueline, & Morrison, 1995), (2) how parents, professionals, and students felt about inclusion (Bennett, Lee, & Lueke, 1998; Fisher, Pumian, & Sax, 1998; Moberg, Zumberg, & Reinman, 1997; Palmer, Borthwick-Duffy, & Widaman, 1998; Ryndak, Downing, Morrison, & Williams, 1996); and (3) the general education room as a medium for learning and participation (Hollowood, Salisbury, Rainforth, & Palombaro, 1995; Logan & Keefe, 1997; Logan & Malone, 1998). Definitive research addressing the usefulness of a multitude of inclusive practices is lacking (Meyer, Park, Grenot-Scheyer, Schwartz, & Harry, 1998).
Barriers

Many innovative programs and practices developed and validated in research communities have not been subsequently adopted by typical schools (Ayres, Meyer, Erevelles, & Park-Lee, 1994; Wang, 1984; Wang & Zollars, 1990). Schwartz, Armony-sivan, 2001) stated: “This gap between the development of effective intervention strategies and widespread adoption in educational settings is easily acknowledged by both researchers and practitioners and, in fact, has become part of the education folklore” (p. 405).

Most service delivery models have failed to make effective and inclusive practices readily available and accessible to students with disabilities (Danielson & Bellamy, 1989; U.S. Department of Education, 1995b). After almost 20 years of specific federal support through IDEA, P.L. 101-476, fewer than half of the students who received special education services graduated with a diploma (U.S. Department of Education, 1994). According to the National Longitudinal Transition Study, only 20% of students with disabilities were independent in the domains of work, residential activities, and social activities 3 to 5 years after completing high school (Wagner, 1993).

To many, accommodating the needs of children with disabilities, especially children with intellectual disabilities or those considered severely disabled, seems insurmountable. Adaptive devices, behavioral disruptions, unusual verbalizations, and limited social abilities are outside the realm of experience and understanding of many educators. These realities associated with disabilities became correlated with the fact that
educating children with disabilities is expensive and far too challenging. Special education appeared to be pointless and counterproductive to those who concluded that disability was the cause of poor educational achievement. People who drew such conclusions questioned how a teacher's time and resources could be spent on these children at the expense of normal students who could "really learn something."

Historically, when students with disabilities failed educationally, they were pitied, and then society attempted to distance itself from them and their families and their educational needs (Trent, 1994)

**Funding**

A primary barrier to educating children with disabilities in general-education settings was the funding formulas in which financial rewards for segregated placements far outweighed the financial incentives for inclusive placements. When enacted in 1975, PL94-142, the predecessor to IDEA, provided for a gradually increasing percentage of federal aid, beginning with 5% of the national average per pupil expenditure (APPE) in FY 1978 and rising to 40% of APPE in Fiscal Year (FY) 1982 and thereafter. In practice, however, federal support never exceeded 12% (Verstegen, 1994).

The basic source of funding for special education is IDEA, Part B, which in FY 1994 amounted to $2,149,686,000 to the states, an allocation of $413 per child (U.S. Department of Education, 1995). Ninety percent of total funding for special education consisted of state and local district funds. From 1970 to 1975, federal funding (as a result of PL 91-230) was based on the total number of children ages 3-21 in a state. This called for a population-based formula. A new formula was adopted in 1975 with passage of
PL94-142, the new formula was a flat grant based on the number of students identified for special education services—up to 12% of the total student population. This is called an identification-based formula. Some argued that the federal entitlement program caused states to lose money; for example, at one time, the average cost of assessment, which was necessary to identify students, was $1,206.00, whereas, the average federal Part B allocation was $411.00 (Tucker, 1989). There were proposals to change the federal funding formula, based on IDEA, to a more neutral system, in effect returning to the federal funding formula used prior to 1975.

It was at the local school district level that the consequences of funding decisions at the federal and state levels played themselves out. Nationally, local governments provided approximately half of the funding for special education services. The local school districts were also the locus for taxpayer reactions concerning education costs. Local funding issues were only a part of the equation regarding the educating of students with intellectual disabilities. Kane (1993) has argued that funding patterns and program decisions were intimately linked.

As school districts tried to change the structure of special education and integrate children with disabilities into regular classrooms, the funding structure that was originally designed to support a separate system became an impediment. The funding structure itself, with its rules, forms, reimbursable costs, and "allowable" costs, became a disincentive to change. There continues to be more incentive to maintain a separate segregated system.
Limited Outcomes

The educational outcomes for youth with disabilities have been dismal (Fisher, 1996; Wagner, 1993). Espinosa and Ochoa (1992) documented a 6-year longitudinal study of the educationally diverse and low-income students within the context of state and national education reform initiatives. Their study reveals the inadequacy of the "deficit model" for explaining poor school achievement among certain groups. Similarly, special educators have been scrutinizing and abandoning a deficit model that has long influenced special education approaches and philosophy (Skrtic, 1991). Nonetheless, Sautter (1994) concluded that the deficit model dominates education. His review suggests that environmental issues eventually become viewed as student deficits. Eventually, as educators, policymakers, and the public attempted to overcome these deficits, they established negative stereotypes of, and discrimination toward, students (Atkins, 1995). Nieto (1996) argues that racism, other forms of discrimination, and limited expectations of students' abilities have a direct impact on achievement. She proposed that these practices are pervasive and lead to categorizing people on the basis of obvious and subtle traits. For example, the visible or physical characteristics of a student with Down syndrome, combined with his or her intellectual disability, leads educators to presume low potential. With that, fixed expectations are developed; resources, policies, and practices, both material and psychological, are metered accordingly. With less support, student achievement is diminished and a self-fulfilling prophecy is created.

Attempting to integrate students with significant disabilities tells us a lot about the ways in which our schools are unimaginative, under-resourced, unresponsive, and simply inadequate (Sapon-Shevin, 1996). Integration did not create these problems, but it shows
us where the problems are. Children who stretch the limits of the system make it painfully clear how constricting and narrow those limits are. Effective integration strategies reveal the ways in which our educational system must grow and improve in order to meet the needs of all children.

Impact

Fisher, et al. (1998) studied the impact that severely disabled students' placement-and-service models have had on non-disabled high-school students' attitudes. Findings indicated that the non-disabled high-school students recommended a continuation of inclusive education, which was consistent with several recent studies (Evans, Salisbury, Polambaro, Beryman, & Hollowood, 1992; Peck, Donaldson, & Pezzoli, 1990; York & Tundidor, 1995). The conclusions were also consistent with two other studies related to inclusion and students with severe disabilities (Helmstetter et al., 1994, Kennedy & Itkonen, 1994). Both studies focused on the social network and interactions between students with and without disabilities. Conclusions in both studies indicated that the integration benefited all students.

Although the results were similar, the uniqueness of Fisher et al. (1998) was the specific questioning of the students without disabilities regarding the practice of inclusive education and whether or not it should have continued. This study asked the classmates of the students with Down syndrome for their impressions. This investigation was directly tied to actual experiences shared by the students with Down syndrome and their non-disabled peers.
Labels of Mental Retardation

Before 1960, mental retardation was defined as incurable, not something that can be changed, without hope for even amelioration. Today, the definition is left open for discussion since retardation is defined functionally (low IQ score and adaptive limitations). There is still widespread understanding among many professionals, and citizens as well, that mental retardation is essentially incurable, a chronic condition.

Mental retardation is not a very descriptive or revealing term; it cannot convey an adequate picture (Dybwad, 1999). With the introduction of the intelligence test, developed by Binet in France and brought to this country by Goddard, it became an accepted practice to relate terms to specific IQ scores. Words like idiot, imbecile, and moron were the first terms used to label children and adults with intellectual disabilities. Later, severe, moderate, and mild were used to describe the scores or what was believed to be degrees of mental retardation associated with various IQ scores. Such static, unchanging labels were commonly accepted, leading to the belief "once retarded, always retarded" (Dybwad, 1999). Such terms were tied to a person's level of functioning, which had far-reaching consequences for a person's lifetime, because that label was the key to decision making about services that a person would or would not receive.

In speaking of the meaning of the term mental retardation, Trent (1994) defined it as a "construction whose changing meaning is shaped both by individuals who initiate and administer policies, programs and practices, and by the social context to which these individuals are responding" (p. 2). He argued that the term has sometimes been used in the name of science, and sometimes in the name of economic necessity. In every case,
however, it has been used for the purpose of controlling people perceived to be a threat, an inconvenience, or a societal drain.

**Down Syndrome**

Down syndrome is a genetic condition that includes chromosomal abnormalities and is associated with mental retardation. Children with Down syndrome usually have below-average intellectual functioning with deficits in adaptive behavior. Students with Down syndrome are often described as mentally retarded, intellectually or cognitively disabled, or severely disabled. At the beginning of this century, many medical reports were published describing additional details of abnormal findings in persons with Down syndrome. Progress in the study of chromosomes in the mid-1950s allowed more accurate studies of human chromosomes, leading to Lejeune's discovery more than 40 years ago that children with Down syndrome have one extra #21 chromosome (Peuschel, 1990).

The appearance and functions of every human being are primarily determined by genes. Likewise, the physical characteristics of a child with Down syndrome are shaped by the influences from their genetic material. Since children inherit genes from both mother and father, children with Down syndrome resemble their parents. Yet, because of additional genetic material on their extra chromosome #21, children with Down syndrome have bodily characteristics that make them look different from children without disabilities. Children with Down syndrome share many features in common and look somewhat like each other. Although some of the characteristics occur at a high frequency and are considered typical of this syndrome, they do not interfere with the
child’s abilities or render him unattractive. The size and shape of the child’s head is smaller and slightly rounder than typically developing children. The child’s face may have a somewhat flat contour. The eyes are normal in shape with eyelids slightly slanted. The size and structure of the ear is sometimes altered. The mouth is usually smaller and the tongue may be slightly protruding. The neck of a child with Down syndrome might appear broad and stocky. On occasion, the chest may have a peculiar shape. Heart and lung problems affect 40% of children with Down syndrome. The fingers and toes of the child are usually shorter than a typical child’s. The combined physical characteristics of a child with Down syndrome may lead people to assume a level of disability that is more significant than indicated by IQ and adaptive behavior alone. This can lead to unsound decisions as they relate to the delivery of educational services and social opportunities.

The boys in this study all have physical characteristics that would lead one to believe they have Down syndrome. Their physical characteristics do not, however, impede their vitality or interfere with life’s essential joys—receiving love, giving it, and just being a kid (Will, 1993).

Intelligence

A narrow view of intelligence has cast a long shadow over schools for the past century. As long as it was assumed that individuals could be arrayed in terms of a single intellectual metric, it followed that the majority of students would be considered "normal," and those who did not pass the metric mark would be classified into special-education categories (Smith, 1998).
The inadequacies of current classification practices went beyond the conceptual problem of defining disabilities. Experts indicated that the instruments used to classify children were often inappropriate and, even worse, of questionable reliability and validity (Salvia & Ysseldyke, 1987; Sattler, 1988; Ysseldyke, Algozzine, Regan, & Potter, 1980). Moreover, studies had shown that those who administered the tests and made placement decisions were often not knowledgeable enough to interpret the results appropriately (Davis & Shepard, 1983; Gartner & Lipsky, 1987; Ysseldyke & Algozzine, 1983; Ysseldyke, Algozzine, & Epps, 1983; Ysseldyke, Thurlow, et al., 1983). The inadequacy and misapplication of assessment reflected another difficulty in educating a student labeled intellectually disabled. All too often, an assumption was made that there was a certain form of ability of intelligence on which all children can be readily compared, and that children can be reliably rank-ordered in terms of intellectual power (Lipsky & Gartner, 1997).

Smith (1998) argued that "grouping students by age and ability" really meant segregating them according to inexperience and inability, as if the aim were to make it impossible for students to help or learn from each other. In special-education classrooms, this put an enormous burden on the teacher, who became totally responsible for teaching a group of helpless pupils, unable to depend on any of them to help each other. Most of the segregation that has been part of special education was forced by school district personnel, not freely chosen by the parents of the child with a disability, and has not been decided on a case-by-case basis (as IDEA requires) (Buswell, et al., 1999). Often, parents are forced to accept segregated special-education services or nothing and are never presented with a range of options. Moreover, it is not clear that segregating
students with disabilities is directly related to a legitimate educational purpose (Sapon-
Shevin, 1996). Kliewer (1999) stated that the notion that children with severe disabilities
inherently require separation from rigorous academics is a dangerous presumption.

**Teacher Preparation**

Although PL 94-142, the Education for All Handicapped Children Act of 1975, required the development of personnel preparation programs that required "state-of-the-
art" practices (Gilhool, 1989), there has been a persistent, marked gap between
understanding of "best practices" and their implementation (Williams et al., 1990).
Although special-education practices have improved, in both design and implementation,
there continue to be substantial inadequacies in teacher education programs, both pre-
service and in-service. Teacher education programs and licensing continues to perpetuate
a dual system in education. There remains a need to break down the barrier between the
separate systems that continue to "limit the scope of instructional methodology" (Mercer,
Lane, Jordan, Allsop, & Eisele, 1996, p. 234) available to all teachers. With general-
education teacher preparation programs focusing on whole class instruction and special-
education teacher preparation programs focusing on meeting individual needs, the
dilemma of meeting the needs of the whole class versus meeting the needs of individual
students has not been adequately addressed (Vaughn et al., 1995). At the early childhood
level, Miller (1992) described teacher training programs as "immoral and inefficient" (p.
39).

There are several factors that influence teachers' motivation to grow and change.
They included (1) perceived needs or dissonance between current practice and desired
learning outcomes, (2) active learning linking content to practice, and (3) development of
ew group norms (McCollum & Catlett, 1997). Rainforth (2000) pointed out that
this is difficult to honor in a geographic region where segregation of students
with severe disabilities is common. It is difficult to honor when teachers
enrolled in graduate programs in special education perceive themselves as
having no responsibility for inclusive education of students with severe
disabilities. This situation was used as an excuse for special education faculty
members in universities not to accept the challenge of teaching content that
teachers need to learn (i.e., innovations for inclusive education). The result then
is a cycle of disempowerment: Teachers are not prepared to support students
with severe disabilities and thus refuse responsibility; as a result, teachers are
not responsible for including students with severe disabilities, they did not
perceive dissonance or needs related to real problems, and lack the motivation
required to learn about innovative practices; as a result, teachers are not
prepared, and so the cycle continues. (p. 90)

Special-Education Teachers

Besides the students with severe disabilities, special-education teachers in the
self-contained classrooms also experience exclusion from general-education classrooms.
Their exclusion is extreme and isolating (Ferguson, 1987). They are the marginalized
(Stonequist, 1937) members of the teaching profession, spending their professional years
outside of the general-education culture. Through training and experience, they are
socialized into the special education culture of pathology and separateness (Skrtic, 1991).
If we expect students with significant disabilities to experience effective inclusion, we
need to be preparing teachers differently. From course strategies (Rainforth, 2000) to
"Dual License Programs," there is a need to directly and specifically teach inclusive
practices, especially in the face of few local examples to illustrate (Ferguson, 2000).

Ayers, et al., (1994) surveyed special-education teachers about the difficulties of
implementing validated practices in classrooms and found that teachers reported lack of
time and lack of administrative support as barriers to implementing inclusive practices. They speculated that many schools did not have the financial or community support to do more than maintain existing services.

Teachers must be prepared to meet children's needs along a broad continuum of developmental and personal characteristics. In their review of research on staff training in nine states, Scruggs and Mastropieri (1996) reported that only 29% of 2,900 respondents indicated that general-education teachers had sufficient training to feel confident in meeting the needs of students with disabilities. Yet, in their review, respondents questioned the effectiveness of typical inservice training.

The Role of Parents

Attention has been focused on parents' perceptions regarding transitioning students with disabilities from self-contained to integrated educational settings (Hanline & Halvorsen, 1989) and educational activity preference (Hamre-Nietupski, Nietupski, & Strathe, 1992). In the body of research on parents, relatively little attention has been given to investigating the perceptions of parents on the practice of inclusion. Parents' perceptions of their children's educational outcomes in inclusive settings are critical to the increase of this practice (Heller & Schilit, 1987), because parents and their children are the most affected by the success or failure in achieving desired outcomes. Ryndak et al. (1995) investigated the perceptions of parents of 13 children with moderate to severe disabilities in inclusive general-education settings. Findings indicated that, regardless of the age of their children, parents of all 13 students reported very positive perceptions.
Parents reported academic, behavioral, and social outcomes that they felt would not have happened without the transition to general-education classes.

Miller et al. (1992) compared the attitudes of parents whose preschool children both with and without disabilities received services in segregated and integrated programs. Parents were generally favorable in their attitudes toward integration, regardless of whether their child was placed in a segregated or integrated program. Giangreco, Edelman, Cloninger, and Dennis (1993) investigated the perceptions of parents whose children without disabilities had a classmate with severe disabilities. Findings indicated that parents’ perceptions were positive and that their children had been affected positively through interactions with a classmate who had disabilities.

**Limited Progress**

Despite the trend throughout U.S. history toward including all students in mainstream education, people made many attempts to slow, stop, and even reverse this trend. Despite mandates for the placement of students in the least restrictive educational environments, some states have shown no progress in this area, and some have even increased restrictive, segregated placements. Likewise, some states made their teacher certification more rigidly categorical, and some developed segregated schools for students with disabilities (Stainback & Stainback, 1992). Some scholars and researchers have argued against the integration movement (Fuchs & Fuchs, 1994; Kauffman, 1993; Kauffman, Gerber, & Semmel, 1988; Lieberman, 1988). Their research, for the most part, has been focused on students who are labeled *learning disabled* and carry a label in educational settings known as LD. They argue for specially designed instruction for
students who struggle to learn in the ways that students are typically educated. They believe that separating the students to address their learning differences is justified.

Specialized research projects and model programs demonstrated the effectiveness of inclusive practices that have produced positive effects, but if the supports, resources, and practitioners' skills needed to successfully implement such programs are not readily available in every community where a student with mental retardation should be educated, the new knowledge lacks ecological validity (Gaylord-Ross, 1979), regardless of its empirical validity. In their article on educational validity, Voeltz and Evans (1983) critiqued the traditional research-to-practice model and called for the development and validation of strategies more suitable for important real-life issues, particularly in the investigation of any area of meaningful outcomes in actual schools, communities, and families. My study provides ecological validity and practical application (of inclusive strategies) under typical circumstances (Odom, 1988).

Discussions about inclusion have moved beyond the borders of special-education circles. For example, leading general-education journals such as The Elementary School Journal (Alper & Ryndak, 1992) and Educational Leadership (Villa & Thousand, 1992) have published articles on how full inclusion might be accomplished. Newspapers such as USA Today (Kelly, 1993) and The Wall Street Journal (Lieberman, 1994) published articles describing full inclusion to the general public.

Despite the existence of laws, policies, and initiatives, the practice of educating students with intellectual disabilities in regular education classes has remained uncommon. The information gained from this study provides professionals with information that may help schools to consider how to include children with intellectual
disabilities in their neighborhood schools. Research that delineates successful inclusive practices and potential benefits may help to dismantle some barriers to inclusion within schools.
CHAPTER 3

METHODOLOGY

*All of us lead storied lives on storied landscapes.*

—Mary Catherine Bateson

Introduction

Qualitative case studies provide intensive, holistic, and descriptive analysis (Merriam, 1988; Wolcott, 1994). Three boys in middle school who have Down syndrome and have participated in regular education classes in public schools for 5 or more years were selected for this study. That is, they were deemed members of a regular education class by their educational teams, including their parents, and received specially designed instruction in those settings (where the majority of students were considered not disabled).

Case studies are increasingly used as a research tool (Hamel, 1993). They contribute uniquely to our knowledge of the individual, the educational organizations, as well as the families, communities, social, and political phenomenon surrounding each student (Yin, 1984). A case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident. In other words, this study covers contextual conditions surrounding the experiences of three students in middle school. According to Yin (1994), an exemplary case study is likely to be one in which: (1) the individual case or cases are unusual and of general public interest, (2) the
underlying issues are nationally important, either in theoretical terms or in policy or practice, and (3) they are both of the preceding. The cases selected for this study included three male students who have Down syndrome and had been attending regular education classes for all of their educational years.

The students selected are a small but growing number of students who are considered severely disabled and attend regular education classes. The current high use of self-contained settings, in spite of IDEA (originally passed in 1975 as P.L. 94-142), depicts the subjects of this study as unusual and of general public interest. The underlying issues reflect the challenges of theory to practice (Meyer, 1991), social validity, and ecological validity (Gaylord-Ross, 1979).

According to Bogdan and Biklen (1992), two of the purposes of qualitative research are to provide "rich description" and to understand the participants' perception of the phenomenon under study. Answers to the research questions in this study could not be found in numbers, percentages, or through forced response mechanisms (Ferguson, Ferguson, & Taylor, 1992). Interviews, observations, and the students' school records contributed to the data that were used to (1) describe the participation of students with intellectual disabilities in middle schools, (2) describe the experiences of the various professionals and para-professionals who support the students, and (3) describe the experiences and perceptions of the students' parents and the students' friends.

**The Purposive Sample**

The focal participants in this study included three male middle-school students who have Down syndrome. A purposeful sampling was used based on the fact that the
students selected would most closely reflect the purpose of this study while at the same time, provide me with information-rich cases to analyze and interpret. A list of the attributes essential to this study (LeCompte & Preissle, 1993) was created and used to select the students: (1) Down syndrome and a label of mental retardation, (2) between the ages of 11 and 14, (3) lives with both parents, (4) lives in the state where the study was conducted, (5) attends their neighborhood middle school, (6) have attended regular education classes since preschool, (7) is considered "fully included" by the parents, (8) is considered "fully included" by the school team, and (9) agrees to participate in this study.

**Selection Process**

The identification of the students in the study began with telephone communication with the Arc, formerly known as The Association for Retarded Citizens. Arc is a national organization that was established by parents of children with mental retardation more than 50 years ago to develop advocacy skills and establish legislation that would address the needs of children with disabilities. There are state and local chapters throughout the country. Arc's primary focus is advocacy for all individuals who have mental retardation. I gave my name and communication information to the Executive Director of the state organization, asking her to give it to parents of children with Down syndrome who are in middle school. Additionally, I contacted the President of the state chapter Arc, who has a son with Down syndrome and has relationships with other mothers who have children with Down syndrome. From this effort and personal recommendations, I contacted nine parents who potentially could meet the criteria for this study. There were three students out of the initial list of nine who met all criteria for the
study. All of the students identified from the list lived in towns in the state where this study was conducted, that would be considered rural or suburban. I made a concerted effort to identify a student in an urban setting. This would have been ideal, in that three students would have been from three different community environments, thus providing me with information about the differences in the school communities. The problem was that there were no students in the urban settings who met the criteria as outlined. The three students for this study were identified and the parents and school personnel agreed to participate in this study.

This study describes the participation of students with intellectual disabilities in middle school. Descriptions include the components or attributes of each student’s program and experiences that contributed to his success. This study also describes what effect the student’s inclusion has had on school personnel, classmates, and the student’s parents.

Data Collection Techniques

Introduction

Data were collected initially through a focus-group interview with the six parents of the students. I then scheduled opportunities to observe the students and conduct semi-structured interviews with the professional and para-professional members of the students’ school teams. The parents of the three boys and the team members in the middle-school setting identified three or four friends of the students who then participated in semi-structured interviews. The students’ school records and work samples were used to further understand their educational program. As required by law, each student who
receives special-education services has an Individualized Education Program (IEP) that provided me with a common basis for comparing each student's program.

All of the interviews and observations were videotaped by a trained technician. The data provided me with the opportunity to review what had occurred through each phase of the study. I transcribed all of the videotapes, which gave me a written script for analysis. Field notes, a journal, and ongoing communication with the parents and team members also contributed to the data collected for this study.

Interviews

According to Bogdan and Biklin (1992), qualitative research is an “umbrella term to refer to several research strategies that share certain characteristics. The data collected have been termed soft, that is rich in description and not easily handled by statistical procedures” (p. 2). The focus of this research is to obtain an understanding of people’s perspective (Taylor & Bogdan, 1984, p. 6) of other people’s experiences and the meaning they make of those experiences (Seidman, 1991, p. 3). One strategy used in qualitative research is interviewing (Seidman, 1991; Taylor and Bogdan, 1984), which is a purposeful conversation between two or more people, directed by one to gather information from the others (Morgan, 1993). According to Patton (1987), the purpose of interviewing is to allow us to enter the other person’s perspective (p. 109).

Focus Group Interview

The focus group is an information-gathering process that brought the students’ parents together at a centralized location to respond to questions on the topic of interest
The following considerations contributed to the quality of the focus group in this study:

1. **Clarity of purpose**: The purpose of the focus group was to bring together the six parents of the students to answer questions, share their experiences with each other, and provide me with insight regarding their individual experiences. Subsequent to the parents agreeing to participate in this study via telephone interviews and discussions, the parents each received a letter describing the study in detail (taken from Human Subject Review Board permission form; please refer to Appendix A). The letter identified the beginning and ending time of the meeting, the location of the meeting, the importance of signing the consent form for them and their son, and what to bring to the group meeting (a picture of their son and the names of three friends who have supported their son), as well as directions to the location of the meeting. The meeting was conducted in my home. Given that the group met on a weekend, the location of my home was central to the three couples, the environment was conducive for such a meeting, and it was cost effective.

When the focus group convened, the parents were given individual folders. In the folder was a document titled Focus Group Instructions. (Please refer to Appendix B.) The instructions described the purpose of the group, the people who would be observing and videotaping, the amount of time that would be allotted for each question, my role in the process, the importance of confidentiality (by referring to people by their role and not their full names), and the importance of having only one person speak at a time. The folders were color-coded by families, and each participant was given the eight questions, each on his or her own page (to provide room for written responses). Each participant had
his or her own folder with the questions in it, a pen, and additional paper. The participants were given the opportunity to ask questions for clarification before the first question was posed.

2. Appropriate environment: The focus group was conducted in a room that was spacious and comfortable. The lighting was natural (from the sun) and the climate was 72 degrees Fahrenheit. I rented a round table and eight chairs to accommodate eight people. The table was covered with a cream-colored linen table cloth. Food and drinks were provided before the group began to work. Ice water was available throughout the interview. The participants spent 3 hours (1:30 to 4:30 p.m.) in the interview with a 10 minute break at 3:00 p.m.

3. Sufficient resources: The focus group participants were given the questions at the time of the interview. (Please refer to Appendix C.) I decided to provide the questions only at the time of the group meeting, thinking that providing the questions in advance would have allowed some members of the group to prepare answers ahead of time, which may have distracted from the spontaneity of the discussion. Waiting until the group was together made the response opportunities more equitable and provided natural opportunities for them to elaborate on their responses. The session was videotaped, audiotaped, and scripted by the researcher and an independent observer. The room was set up and organized with all of the materials necessary prior to the arrival of the participants.

4. Appropriate participants: The six participants in the focus group met the criteria for participation in the study. They agreed verbally and on a signed consent form to participate. The participants did not know each other prior to the focus group meeting.
These parents confirmed that their sons were students in middle school, had Down syndrome, and had been educated in regular education classrooms since preschool.

5. **Skillful moderator**: I was the moderator for the focus group interview. Twenty-four years of experience as an educator and consultant, and active participation in research instruction contributed to my ability to facilitate the interviews. I piloted a similar group with parents in a school setting using a focus-group approach. I read the directions to the group, asked the questions, used phrases to encourage participants to expand on their responses, and managed the timing of the questions. The independent observer provided feedback to the moderator subsequent to the end of the group meeting. Feedback included "well executed," and "done with precision."

6. **Effective questions**: An interviewer can ask several types of questions to stimulate responses from an informant. Strauss et al. (1981) offer four major categories of questions. This study used hypothetical, interpretive, and ideal-position questions. The questions were set in a logical sequence and designed to provide the participants the opportunity to share the salient aspects of their son's educational experience. The focus group questions were:

   a. Who are you? Tell us about your family and a favorite story about your son.

   b. Describe your son's current educational program. Are you satisfied with the program?

   c. What have been the most successful elements of your son's educational program?
d. What, if any, barriers (to learning and participation) have you encountered in your son's educational experience?

e. If you could change any aspect of your son's educational experience, what would that be?

f. As you look to the future, what is your vision for your son?

g. If you could give advice to parents of young children with intellectual disabilities (about education), what would you tell them?

h. What final statement would you like to make regarding educating children with intellectual disabilities?

7. Careful data handling: Data were collected using videotape, audiotape, scripting, transcripts, an independent observer, and written notes from each participant. Immediately following the session, I reviewed the videotapes with the independent observer. Together, we tape-recorded our impressions. We then watched the videotape, identified the themes, identified the most notable quotes, and confirmed the participants' responses. The 3-hour videotape was transcribed for analysis.

8. Systematic and verifiable analysis: The focus questions were designed to follow a prescribed, sequential process (Morgan, 1993). There were two independent researchers analyzing the data from the focus group during the analysis phase after all of the data were collected. The final question asked of the participants was to clarify their conclusions (Morgan, 1993). Verification was sought from the participants during the responses as well. Subsequent to the observations and school team interviews, impressions and interpretations were confirmed with the focus group participants (to validate some of the attributes, components, and perceptions shared by the parents). I
elected to hand-code the data from the focus group as well as the data from the observations and semi-structured interviews. Computer applications were considered for coding but were determined to lack the sensitivity needed for analysis of this particular topic. One threat to quality of systematic and verifiable analysis is the role of the moderator as researcher. Fatigue was not a factor in this situation, in that it was only 3 hours, it was well anticipated, and this situation was a novel aspect to this study.

9. **Appropriate presentation:** The data from the focus group were analyzed and are described in chapters 4, 5, and 6, the chapters that provide the reader with the culminating information about the boys educational experiences. These chapters include rich descriptive language to enhance verisimilitude (Van Maanen, 1988).

10. **Honoring the participants, client, and method:** Respect, confidentiality, and gratitude were honored before, during, and after the focus group. This study included a high degree of sensitivity to the language used in relation to children with special-education needs. The sensitivity of sharing experiences that may have proven to be challenging to the participants was foremost in my mind. All of the participants were pleased with the activity and provided positive feedback to me at the conclusion of our time together. The relationships between the participants have expanded since the focus group was convened, adding a new network of support to the parents who continue to advocate for quality educational opportunities for their children.

**Semi-Structured Interviews With the School Teams**

Most interviews in qualitative research are semi-structured (Merriam, 1998). The questions posed to the team at school were structured similar to the focus group conducted with the parents. In preparation for the opportunity to observe the students at
school and interview their teams, the parents provided me with signed permission forms to be sent to the schools' principals. The parents also provided me with a list of students who they feel are good friends or supporters of their son. Both of these items were attached to a letter sent to each principal after the focus group was convened. (Please refer to Appendix A.)

The principal's letter included a description of the research study. It included a request to observe the student, meet with the student's team to conduct the interviews, meet with the students who are friends with the boys in the study, and obtain work samples and a copy of the IEP. The approximate amount of time commitments needed were also identified.

Each principal responded within 2 weeks. All three principals welcomed the opportunity for their teams to participate in the study and assured me their full cooperation. Some of the teams reportedly met on a regular basis. In an effort to minimize intrusion and be considerate of the time that was requested, I offered to meet with the teams during their regular meeting times.

The challenge was to get all of the questions answered within the time frame allowed. To that end, I communicated with the educator identified by the principal. When students with disabilities receive services from a number of professionals, there is usually a case manager who coordinates the communication and data associated with implementation of the IEP. The questions were not shared in advance, for the same reasons that the focus group questions were not shared. During the team meetings, I facilitated a consensus process using a graphics approach (Mount, 1995). That is, the questions were written on large paper for all team members to see. One of the teams did
not have the benefit of the graphics approach due to an unexpected change in the location of the meeting and the lack of wall space and time allotted. Team members were also provided with their own page of questions (see Appendix D).

I asked the team to respond to the following questions:

1. Who are you and what role do you play in the student’s life?
2. Tell us your favorite story about name of student (N).
3. What are the most successful elements of N’s educational program?
4. What, if any, barriers to N’s learning and participation have you encountered?
5. If you could change any aspect of N’s program, what would that be?
6. As you look to the future, what do you see for N?
7. What advice would you give other educators and team members who will have students with intellectual disabilities in the future?
8. What final statement would you like to make concerning this issue?

All of the individual responses were collected at the conclusion of the meeting. The colorful graphics that culminated the team’s responses was transcribed and used for triangulation. The meetings were videotaped, transcribed, and coded for analysis. Field notes and journals were used to further detail the experiences I had with the teams.

**Semi-structured Interviews With Classmates**

The parents of the students in this study identified three students from school who they considered to be friends or supporters of their sons. The letter that was sent to the principals included the names of the students identified. Through the principal, I arranged to meet with the students during a non-academic time (such as lunch, Physical Education
class, or at the beginning of the school day). During the time selected, I facilitated responses among the students by having them sit together and gave them the opportunity to respond either individually or as a group. The student's friends were given the list of questions at the beginning of the meeting. (See Appendix E.) Due to space limitations in one situation and limited time in another, I decided not to use the graphics approach. I decided that just sitting with the students at a table or in the small room provided allowed the students to be more interactive with each other, thus giving me more dialogue to analyze. They responded to the following questions:

1. What is your name?
2. How long have you known N?
3. What fun experience have you had with N?
4. Do you see any problems? What are they?
5. How would you change things?
6. What do you think high school will be like for N?
7. If other students ask you about N, what do you tell them?
8. Do you have any thoughts about how things have changed?
9. Is there anything else you would like to share?

I recorded the students' responses while the session was videotaped by a trained technician. Some of the students wrote their responses on their paper, while others chose not to. Some students drew pictures or symbols during the interview. The papers were collected at the conclusion of the meeting. Field notes and journal entries were completed and used for analysis.
Observation Procedures

Observation is a research tool when it (1) serves to formulate research purpose, (2) is planned deliberately, (3) is recorded systematically, and (4) is subjected to checks and controls on validity and reliability (Kidder, Sellitz, Wrightsman, & Cooks, 1981, p. 264). The purpose of the observations was to offer a firsthand account of the students in their middle-school environments and to triangulate emerging findings with the semi-structured interviews and documents (Merriam, 1998). Through the principals, I scheduled direct observations that occurred during a typical school day (determined by the students' teachers) and a mutually agreeable day. LeCompte and Preissle (1993) state that what to observe depends on the topic and conceptual framework, "the data that begins to emerge as the participant observer interacts in the daily flow of events and activities, and the intuitive reactions and hunches that participant observers experience as all these factors come together" (p. 200).

Qualitative research methods call for the investigator to enter the lives of the persons being studied as fully as possible (Edgerton, 1984). In this study, each student was observed for 1 or 2 typical days in his middle school. During this time, I wrote detailed field notes, described the layout of the environments, and interacted with the students and teachers when appropriate. My role in the observations could be best described as moderate. As an objective observer collecting data for this study, I determined that active participation for me in the middle-school classes was not appropriate. Efforts were made to assume a role that was distant from the teacher (by not providing any assistance or direction to students), yet interactive to the point where I was able to gain an understanding of the students' experiences by interacting with them and
their peers before and after classes. I also had many opportunities to interact with the teachers before and after classes. All observations were videotaped by a trained technician to be used for analysis.

I observed the students in their classrooms and all other environments found in a typical public middle school in the state where this study was conducted. I paid close attention to the students' interactions with peers and adults, noting the variety of interactions that occurred in the context of a typical day. There was a focus on the elements of the students' learning experiences that illustrated inclusion, from my perspective.

An observation guide provided a structure for my recording of specific events, strategies, personnel, and salient details in each of the situations. (Please refer to Appendix F.) There are several elements that are likely to be present in any setting (Goetz & LeCompte, 1984; Bogdan & Biklen, 1992; Patton, 1990; Taylor & Bogdan, 1984) During the observations, I described the following:

1. **The physical setting:** The school environments; how the room was furnished, the design of the instructional environment, that is, some classrooms have the desks in the traditional rows facing the blackboard. I noted the configuration of the desks, where the instructional materials were located, the lighting, climate, and location of the classrooms and other learning environments in the school buildings.

2. **The participants:** Who were the people who interacted with the selected students? What was their role? What were relevant characteristics of the people in the students' learning environments?
3. Activities: In the school settings, there was a wide range of classroom activities that I had the opportunity to describe. Activities included academic settings, where the focus of the lessons was on curricular areas such as reading, math, and social sciences. Activities in a middle school include cultural arts, such as music and art, technology education (keyboarding class), physical education classes, lunch, assemblies, extra-curricular activities, and before and after school (or class) socialization. This study describes how the people in these settings connected with the activities, noting the norms, rituals, and rules. The initiation, timing, and termination of the activities were noted.

4. Conversation. In this study, a keen focus was placed on the behavior of the adults toward the students. I noted demeanor, tone, and instructional styles of the adults. Additionally, the classmates of the students were observed, noting the frequency, intent, reciprocity, and unpredictable dynamic aspects of interaction with the student. During the observations, I recorded as many conversations as possible within the various settings, using a tape recorder, video recorder, and pen to paper. I also noted nonverbal behaviors, general climate of the conversation, quotable quotes, and themes across the students' day. The various conversations that each student had reflected the attitudes and experiences of the people around him. I paid particular attention to the nature and tone of the interactions. How people related to each of the boys addressed the research question: What effect does the students' inclusion have on others? Throughout the observations, I attempted to discern whether or not the conversations were typical or influenced by my presence. This aspect is discussed in the implications and themes section of this research.

5. Subtle factors. I described the aspects of the observation that did not fit into a specific category. A middle school is a busy environment with high levels of activity that
could not possibly be predicted. This study addressed what did not happen, especially if I believe it should have, during the observations.

6. Behavior of the observer: The challenge is to combine participation and observation so as to become capable of understanding the experience as an insider while describing the experience for an outsider (Patton, 1990). I did not actively engage in the instructional aspects of the lessons. As an observer in a middle-school classroom there was a degree of influence over the behavior of the instructor and students. To that end, I was identified as a "student who is here to learn about middle schools." I recorded interactions that occurred with participants in the various environments. In addition, I recorded ongoing thoughts and comments as the observation occurred.

The overall time spent on the site, the number of visits, and the number of observations made per visit were not precisely determined ahead of time, which, according to Merriam (1998), is acceptable. The duration for each observation was between 5 and 6 hours, which was equal to a full school day. I returned to two of the schools for additional observation time after determining that there were situations or classes that would give me a better understanding of the students' experiences. In one school, I learned that the students were leaving the school grounds for a field trip on the afternoon of a scheduled observation. The team that supported the selected student met with me during that time. The student did not return to the school setting until the end of the day. Additional observation time was arranged. In another situation, I observed the student on 2 different days to ensure that I observed all of his classes. I then met with his friends to conduct the semi-structured interview.
Data From Observations

The raw data generated during the observations included the following:

1. A *factor-to-consider* sheet was filled out for each class or activity observed.

2. *Video recordings* were made during the semi-structured interviews and for all of the observations. I was accompanied by a trained technician, who recorded the students I was observing. This included the lessons facilitated by the instructor, direct support to the selected students, unstructured times in the student’s day when spontaneous interactions occurred, and every opportunity that was considered appropriate for observation data. I provided the technician with written instructions and I reviewed them with him before the observations began. (Please refer to Appendix G.)

3. *Field notes* were maintained throughout the observations. I recorded impressions, comments and questions that occurred as the observations evolved. The factor sheets, (paper with the headings "what I see" and "what I think" and blank paper) were all on a clip board.

4. Once the observation was completed, I *recorded* overall impressions and comments. Bogdan (1972) and Taylor and Bogdan (1984) advise against talking to anyone about the observation before notes have been recorded. Subsequent to the observations, I cloistered myself for a period of time to review impressions, add detail to the field notes, summarize the observations, and carefully document what had occurred (Lofland, 1971). It was at this time that I used an audiorecorder to articulate my impressions and pose questions that came to mind. Data analysis occurred following each of the observations.
5. Journaling: I initiated the use of a fieldwork journal in August 2000 when the topic of this study was approved. The journal includes ideas, fears, reactions, opinions, experiences, thoughts about methodology and analysis plans, and general reflections about the experience of completing this study. The entries have occurred throughout this study, and will continue until it is defended.

Documents

Documents are a ready-made source of data that this study includes. At their school, all students have cumulative files that may include the following:

1. IEPs (Individualized Education Program plans): The IEP is a written document that outlines a child's abilities and learning needs. It defines the educational program designed to meet the individual needs of a special-education student. It is intended to be a planning document, which shapes and guides the day-to-day provision of special education and related services. It is most useful when it reflects the integrated approach to curriculum and instruction that emanates from a collaborative team process (Rainforth & York-Barr, 1997). The students' current IEPs were reviewed. In the State of Connecticut, the IEP forms are uniform across all districts (since 1998). I compared the three students' IEPs, noting the variations, range of details, and unique aspects of each. These documents contributed to the triangulation of the data.

2. Student work samples: A portfolio is a record of learning that focuses on the students' work and, in some instances, his reflection on that work. It is a collection of students work that tells a story of the students' efforts, progress, or achievements. Portfolios have long existed in many fields, but the concept has recently become popular.
in education during the 1990s. Used as an assessment framework, it is a systematic collection of data that serves to examine the students' efforts, improvements, achievements, and accountability (Danielson & Abrutyn, 1997). The students' portfolios were reviewed and samples of the students' work were copied and used for analysis. I did not compare the students' individual school work or achievements, as each student is an individual learner with his own gifts, strengths, and abilities. The portfolios served to validate my impressions of the students' learning experiences.

3. Report cards: Student achievement in a middle school is communicated to the parents through "report cards." Since students with IEPs often have different reporting requirements, I wanted to find out whether or not the students in my study had the same reporting opportunities as their typical peers. (These documents served as an important topic of conversation among middle-school students.)

4. Lesson plans: Most educational programs require teachers to provide "lesson plans" for the purpose of outlining the objectives of the lesson, the materials needed, and the instructional strategies to be used. During the observations, I requested a copy of the lesson plans to determine if and how the instructional plans accommodated the individualized learning needs of the students in the study. This request was met with a dismal response. Either the lesson plans were so broad that they provided no basis for analysis, or they did not exist as a plan that could be shared with me.

5. Formal and informal assessment data: A student who receives special-education services is evaluated at least annually to determine what special-education supports and services are necessary. Assessments must be conducted by qualified members of the student's team (an educator, psychologist, etc.). The members of the
students' Planning and Placement Team (PPT) collect information from a variety of sources, including observations, interviews, work samples, and formal assessments. Assessments are required every 3 years to determine whether the student still qualifies for special-education services. It also serves as longitudinal data for evaluating instructional strategies and appropriate placement. I reviewed the various assessments that were found in the files for each student in the study.

The State-wide Mastery Tests are given to students in Grades 4, 6, and 8 in the state's public schools. The student's Planning and Placement Teams determine what modifications need to be considered to accommodate students who receive special education services. If the PPT determine that the student should not take the CMT, an alternative assessment (developmental checklist) is used. I reviewed the accommodations or alternatives considered in this process. Only one of the students in the study took the test. Two of the students were deemed exempt, and therefore the checklist was used. The checklist was reviewed to glean the teams' perceptions of the individual student's abilities.

6. Correspondence and other related information in the school records: The students' cumulative files included a wide range of documents. I reviewed all of the records relevant to the students' educational history, noting salient pieces of evidence that could contribute to a comprehensive understanding of the students' experience and the people who support him. During communication with one of the school principals, I learned that a student identified for this study had been the subject of due process hearings, a procedure to settle disagreements between the parents and the school district. The due process hearing allowed an impartial third party, the hearing officer, to look at
issues in which there was disagreement. After evidence was presented by both parties relevant to the disagreement, the hearing officer rendered a decision. There was a significant amount of paper associated with this particular student. I reviewed all of the documents, then identified and analyzed the documents that contributed to the understanding of the history and relationships in this student's life.

The documentary data described were good sources for this study. Analysis of documents lends contextual richness and helped to ground this inquiry in the milieu of the student's learning experiences. This is what the naturalistic inquiry assumes. (Guba & Lincoln, 1981).

Data Analysis

Data analysis in qualitative research is a dynamic process that involves developing insights, holding the insights up to the data, refining the insights, and double checking the insights until a coherent understanding is obtained. Thus, in qualitative research, analysis is inductive. Concepts, insights, and understandings are developed from the data, rather than being formulated a priori (Taylor, 1988) "Grounded theory" refers to concepts and understandings derived from the data (Glaser & Strauss, 1967). A good qualitative research report provides enough information about what decisions were made to enable others to make independent interpretations of their results. The reader must view findings based in the context on how the study was conducted, that is, who was interviewed, how they were interviewed, and how the reader made sense out of what he or she is told, to establish the credibility of the findings and conclusions made. This
increases the understanding of the perspectives of people on the receiving end of our services.

Analysis of the data collected began in the early stages of this project. I have cycled back and forth between thinking about the existing data (educational records) and generating strategies for collecting new and more qualitative data. This approach made analysis an ongoing, energetic, and meaningful process. The following considerations guided me in analyzing all of the data in this study:

The role of the researcher: The process involved in analysis—from selection of the research questions, through interviews, observations, document mining, coding, the creation of displays, data entry, conclusion drawing, and verification—requires sustained awareness and continuous self-correction. Only over time, as the methods themselves evolved and iterated, was I able to produce focused, organized displays that permitted systematic analysis and enhanced confidence in my findings. I maintained a journal from the early stages of this study. The reflections in this journal assisted me in maintaining an awareness of the process and provided me with insight into the evolution of my learning.

Raw data: This includes field notes, notes on the planning process, drafts of questions, pilot responses, correspondence, and audiotapes of thoughts and reflections. All of these items were processed and converted into "write-ups." They were transcribed into intelligible products. These data were then edited for accuracy, commented on, coded, and analyzed.
Document summary form: The documents described in the methodology section were used to identify and understand their significance. A document summary form was used to explain significance. Each document was coded for rapid retrieval and analysis.

Codes and coding: This involved assigning short-hand designation to various aspects of data so that retrieval of specific pieces of data occurred. The designation was as small as a single word, letters, phrases, or a combination thereof. Coding occurred at two levels: identifying information about the data, and interpretive constructs related to analysis. The coding scheme was simple, as in identifying a theme that was illustrated with numerous incidents, quotes, behaviors, and the like. It was sometimes quite complex, with multilevels of coding for each incident or quote (Strauss, 1987; Strauss & Corbin, 1990). The first level of coding labeled passages of text according to content and retrieval. I assigned identifying notations that provided me access when needed for both analysis and write-ups. This rudimentary analysis helped me to move between the emerging analysis and raw data from interviews, observations, and documents. Dey (1993) points out that the term coding is mechanical and at odds with the conceptual tasks involved in categorizing data. Qualitative analysis, in contrast, requires the analyst to create or adapt concepts relevant to the data rather than applying a set of established rules.

Revisiting the conceptual frameworks and research questions helped me in managing this inescapably selective process. A “start list” of codes was identified based on the conceptual framework, research questions, and key variables that I brought to the study. Early on, the codes seemed limiting and less meaningful than anticipated. Thus, various approaches to coding were studied and considered for the best approach to
analysis, including the Strauss (1987) and Strauss and Corbin (1990) approach, involving line-by-line categorizing or labeling that grew as the analysis proceeded. Lofland (1971) suggested that codes in any study can be sorted by phenomenon, graduating from micro to macro levels. Another consideration came from Bogdan and Biklen (1992), who divided codes into 10 categories leading to meaningful interrelatedness. Lincoln and Guba (1985) talked about four operations, suggesting that coding and recoding are over when the analysis itself appears to have run its course—when categories are saturated and sufficient numbers of regularities have emerged. This became evident as I continuously coded the various passages from the interviews and observations. Over time, the themes and codes emerged quite clearly.

Data Representation

There are two basic ways to share interview data. The first is through profiles of individual participants, with the results of the observations, interviews, and documents grouped into categories that make sense. The second approach is to mark individual passages into categories, and then study the categories for thematic connections within and among them. I used both strategies to analyze the data.

Another approach to sharing data places less reliance on words and more on graphics, charts, and matrices (Miles & Huberman, 1984). I decided to use a graphics approach to conduct the team interviews (Mount, 1995). This approach involved taping large pieces of white paper on the walls in a room where the students sat in the center of the room at a table. I used colorful markers to write each question in advance on their
own page. I then recorded the teams’ responses on the paper. The data from the meetings were then transcribed and coded for analysis.

A total of 22 sources of data were used in this study. Table 1 provides the reader with an easy review of data sources, demographic information, roles, and numbers of participants on each team.

The central components of qualitative analysis, according to Dey (1993), include presenting the participants in context, clarifying their intentions, and conveying a sense of process and time. The summaries and impressions developed subsequent to each observation and interview provided me with an interpretation of what occurred. I then compared the data that I collected during the actual interviews and observations with the videotapes that correspond to the documents. Each phase of data collection contributed to a deeper understanding of each boy’s educational experience.

The first presentation of the study’s findings was a descriptive account of my journey, starting with the planning process and ending with the analysis process. Within this frame of information, there were descriptions of the focus group, descriptions of the various observations, team interviews, and classmate interviews. There were records to consider, work samples from each student, field notes, code sheets, and a variety of correspondence documents. I had to determine what would be included and what would be left out from the huge volume of data collected. The data were compressed and linked together in a narrative that conveys the meaning that I derived from studying three students in a middle school who have been included since preschool.
Table 1  
The Various Sources of Data Analyzed in this study

<table>
<thead>
<tr>
<th>Data Sources</th>
<th>Joe</th>
<th>Ned</th>
<th>Carl</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Observation “factors to consider”</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>2. (prompts)</td>
<td></td>
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<tr>
<td>3. Observation videotapes</td>
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<tr>
<td>4. Observation summary and field notes</td>
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<td>X</td>
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<tr>
<td>5. Team interview summary and field notes</td>
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<td>X</td>
<td>X</td>
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<tr>
<td>6. Interview graphics on large paper</td>
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<td>X</td>
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<tr>
<td>7. Team interview videotapes</td>
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<td>8. Friends' interview answer sheets (kids filled out)</td>
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<td>X</td>
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<tr>
<td>9. Friends' videotapes</td>
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<td>X</td>
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<tr>
<td>10. Friends' summary and field notes</td>
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<tr>
<td>11. Parent focus group questions/checklist</td>
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<td>12. Parent focus group videotapes</td>
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<td>16. Field notes (general)</td>
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<td>17. Journal</td>
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<td>18. Reliability (Colleague/Member check)</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>19. Video of student in unique situation at school</td>
<td>X</td>
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<tr>
<td>20. Student records (IEP's)</td>
<td>X</td>
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<tr>
<td>21. Student work samples</td>
<td>X</td>
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<td>22. Letter from newspaper (JP)</td>
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LeCompte and Priessle (1993) believe that ethnographers who "simply describe what they saw" fail to do justice to their data. Significant effort has been put forth to ensure that the reader is not left to his or her own conclusions, risking that the study be trivialized or misinterpreted. For that reason, the analysis moved beyond the basic description to the next level of analysis. I constructed categories or themes that captured recurring patterns that cut across all three cases (Taylor & Bogdan, 1984). These categories or themes were concepts indicated by the data. The categories constructed were systematic and informed, driven by the study's purpose (identifying the successful components of the educational programs, and the effect the program had on others). These categories were constructed through the constant comparison of situations, respondents, practices, and experiences.

A unit of data is any meaningful or potentially meaningful segment of data. It can be as small as one word, or as large as many pages describing a situation. According to Lincoln and Guba (1985), a unit must meet two criteria. First, it should be heuristic, that is, it should reveal information relevant to the study and stimulate the reader to think beyond the particular bit of information. Second, the unit should be "the smallest piece of information about something that can stand by itself, that is, it must be interpretable in the absence of any additional information other than a broad understanding of the context in which the inquiry is carried out" (p. 345). The units of data for this study adhered to these two criteria.

I compared one unit of information with the next, looking for recurring regularities in the data by breaking it into bits of information and assigning these pieces of information to categories or classes and then bringing them together again in a novel
way. The data were also subdivided or subsumed under more abstract categories (Dey, 1993). The names of the categories emerged logically from the data, and the schemes to sort the data reflected the focus of the study. As the data were collected, tentative findings were substantiated, revised, and reconfigured.

Telling stories is one major way that human beings have devised to make sense of themselves and their social world (Mishler, 1986). Throughout this study, I gave each participant opportunities to share favorite stories about the students. The stories provided illuminating examples of the boys' social abilities, personal interests, and actual experiences. It gave the parents, team members, and classmates the opportunity to share their stories with each other, which seemed to be a very positive experience for the participants while providing me with rich data and insight.

Crafting profiles is a way to find and display coherence in the constitutive events of a participant's experiences, to share the coherence the participant has expressed, and to link the individual experience to the social and organizational context with which he or she operates (Merriam, 1988). I provide the reader with background information about each of the boys by describing who they are and what their experiences were like from birth until the time they entered middle school. I describe each of the teams and each boy's educational program. After summarizing my perceptions, I then provide the reader with a story that I wrote as an interpretation (Geertz, 1973). A straight description from the data sources would not have been adequate without interpretation (Eisner, 1991). My intent is for the reader to enjoy a story about each boy while understanding the important events and situations that occurred in the lives of the three boys in this study. My stories "unwrap" or help to explicate their experiences as a student or friend. I accomplished
this by triangulating the data, corroborating with the parents and team members, and analyzing the videotapes and relevant documents. One key to the power of the approach is that it is presented using the words and experiences of the participants.

After each observation, interview, and focus group, I completed field notes and journal entries, and I then audiotaped my impressions. I also verified my impressions with the independent observer and video technician. Telephone communication occurred frequently with various members of the boys' teams, including the parents, teachers, and administrators, to verify understandings and impressions. I also made it a point to interact with each of the boys so that I could understand, to the best of my ability, who they are and what they experienced in their educational programs.

The videotapes were copied from the original digital camera to 1/2" videotape. Two copies of each tape were made for the purpose of having backup tapes or extra copies to ensure their availability for reliability and validity. I observed the videotapes, transcribing all of them by hand, word for word, leading to a combined script and visual display of what had occurred. These data were then compared to the data sheets and field notes generated during the observations and interviews.

I filed and marked passages from the tapes and data sheets into labeled categories. Passages and statements that were considered important were marked and coded. The tapes and data sheets were viewed numerous times, each time with a more demanding eye, and in many instances, with a "reliability" coder who then provided me with confirming or varied perspectives on what had occurred.

The documents reviewed included a wide range of records from each student's school file. They included IEPs, evaluations and assessments, correspondence, legal
documents related to settlement agreements (in one case), other related documents, including incident reports, discipline referrals, and scores from the Connecticut Mastery Tests, or alternative assessments given in place of the mastery tests.

The documents that were found to be the most relevant and useful for this study were the students’ current IEPs and work samples. There were significant limitations in my ability to compare the records. Each school system possessed unique record-keeping systems, and the documents were so varied that it was impossible to compare any documents other than the IEPs and work samples. The richness of the dialogue amongst team members, the children, and the parents provided me with more than enough data to present a holistic, intensive description and interpretation of this contemporary phenomenon called inclusive education.

Trustworthiness Issues

Referring to narrative inquiry, Connelly and Clandinin (1990) write that this genre of research "relies on criteria other than validity, reliability, and generalizability" and that these criteria are "under development in the research community." They note that "each inquirer must search for and defend the criteria that best apply to his or her work" and they propose "apparentness, verisimilitude, and transferability as possible criteria" (p. 7).

Yet, Wolcott (1994) takes another view, arguing that validity is a quality that points more to identifying critical elements and wringing plausible interpretations from them, something one can pursue without becoming obsessed with finding the "right" or ultimate answer, the correct version, the truth (pp. 366-367). For Wolcott, the "something else" is
understanding. This study brings understanding of the concept of inclusive education to the reader.

Qualitative findings have a certain undeniability that is often far more convincing to a reader than the use of numbers (Smith, 1978). In qualitative research, issues of instrument validity and reliability ride largely on the skills of the researcher. Thus, the following considerations apply to this study (Miles & Huberman, 1994):

1. **Familiarity with the phenomenon:** I have actively engaged in the lives of individuals with disabilities and their families for all of my twenty six professional years. I have spent a significant amount of time in middle school setting and have been actively involved in assessing, designing, and supporting inclusive education programs for students of all ages. A significant amount of my professional experience has been spent working with children who have labels of mental retardation.

2. **Strong conceptual interest:** I have studied the phenomenon of educational practices relevant to students with disabilities since 1972. The literature has evolved significantly since the early 1970s, when virtually the only resource available to educators was *Educational Programming for the Severely and Profoundly Handicapped* (Sontag, Smith, & Certo, 1977). I have remained familiar with the literature since then, and possess the passion and persistence that were required to complete this study and make a contribution to the literature.

3. **A multidisciplinary approach,** as opposed to a narrow grounding or focus in a single discipline: My formal and informal educational activities have influenced my skills as a researcher. As a teacher with experience in general education and special
education, I possess the breadth of knowledge and the ability to understand a variety of perspectives that were shared by the participants in this study.

4. Good investigative skills, including doggedness, the ability to draw people out, and the ability to ward off premature closure: The time commitment and financial investment that this study required are representational of my doggedness. Campbell (1975) suggests that an effective qualitative researcher have a thorough local acquaintance with the phenomenon. I am thoroughly familiar with the literature, the population of students being studied, as well as the wide range of practices that exist in a variety of middle schools in the state where this was conducted.

Listening, restating, and expanding are some of the skills that were used to draw people out and engage them in the questions. I used a variety of strategies to ensure comfort and trust in the process. In the focus group creating an environment that was conducive to sharing and perceived as comfortable encouraged the parents to share their stories. Having refreshments at the meeting was positive as well. Meeting the team members during their school day and interviewing them as a group, provided them with positive feedback from each other and provided me with insight as to how they operate as a team. The classmates were easily engaged and motivated to participate. The responses they gave to the questions were enlightening, however, the facial expressions and antics of the children reviewed on the videotapes provided me with the richest data. During the observations, the interactions that I observed helped me to understand and experience firsthand the undeniable benefits of inclusion for the boys in this study.
Closure in this study occurred when I completed all data-collection activities, described, and analyzed the results. This required additional visits to the schools, follow-up telephone communication with participants to verify information, contacting participants to complete member checks subsequent to the development of the profiles, and adjusting some aspects of the study along the way to ensure completeness.

In this study, I was the key instrument. Whyte (1984) suggests that the researcher have “first, intimate, habitual intuitive familiarity with things, secondly, systematic knowledge of things, and thirdly, an effective way of thinking about things” (p. #). I completed this study with the above skills in mind.

One of the assumptions underlying qualitative research is that reality is holistic, multidimensional, and ever-changing; it is not a single, fixed, objective phenomenon waiting to be discovered, observed, and measured as in quantitative research (Merriam, 1998). What is being observed in this study is people's construction of reality—how they understand the issue at hand. Reality, according to Lincoln and Guba (1985), is “a multiple set of mental constructions . . . made by humans; their constructions are on their minds.” Interpretations of reality are accessed directly through observations and interviews. When reality is viewed in this manner, internal validity is a definite strength of qualitative research.

Five strategies were used in this study to enhance internal validity:

1. Triangulation: (Denzin, 1970): Using multiple sources of data and multiple methods to confirm the emerging findings, Mathison (1988) points out that triangulation may produce data that are inconsistent or contradictory. She suggests shifting the notion of triangulation away from “technological solutions for ensuring validity” and instead
relying on a holistic understanding of the situation to construct "plausible explanation about the phenomenon being studied" (p. 17). This study includes layers of triangulation in that the students each have parents, school teams, and classmates who all responded to questions relevant to their experiences with the selected students. The themes and group responses were compared within each case. I also used documents and observation to collect data that contributed to my understanding of each situation. Eisner (1986) uses the term *structural corroboration* to describe the confluence of multiple sources of evidence or the recurrence of instances that support a conclusion. To gain an understanding of each of the boys' educational experiences, I put together bits and pieces of the evidence to form a story that substantiates the conclusions I drew from the many sources of data. Together, these sources of data provided me with evidence to develop a holistic understanding of each of the students' educational experiences and the experiences of the people who support them.

2. *Member checks:* This required taking data and tentative interpretations back to the people from whom they were derived and asking them if the results are plausible. Such checks occurred throughout the study. Member checks played the most prominent role after I wrote a story about each boy titled "A Day in the Life of____." The stories were electronically mailed to the parents, administrators, and some members of the teams to determine whether or not they found my stories and profiles to be plausible. In each case, the feedback was positive and acceptable to all. Some of the feedback was succinct, while in other cases, the participants enjoyed the stories to the point where they commented about the details I had developed. I confirmed perceptions (from the parents' focus group) by sharing data summaries during analysis. I confirmed
interpretations with members of the school teams during analysis of the data. Such
communication was documented and verified throughout the study. All member checks
were documented via electronic mail and are included in the analysis of this study.

3. The observation techniques I used were deliberately planned, recorded
systematically, and subjected to checks and controls on validity and reliability (Kidder, et
al. 1981). The observations in this study were conducted for an entire school day for each
student. I wrote descriptively, recorded field notes, and practiced the art of separating
trivia from detail. I was a participant observer as the circumstances allowed and were
conducive to increasing my understanding of the situation as it happened. I triangulated
the emerging findings. That is, they were used in conjunction with interviews and
documents to substantiate my findings. The observations were videotaped. A “factors to
consider” sheet was used to structure the observation notes, and a layout of each
environment was mapped to provide detailed descriptions where the students were
observed. Subsequent to each observation, the videotapes and transcripts were coded by
me and at least one reliability coder for the majority of the data. Together, these
techniques enhance the reliability of each observation.

4. Peer examination: I elected to use an independent observer for the focus
group. There were also two colleagues who assisted me with internal validity. During
the analysis phase of this study, the independent personnel observed the videotapes,
reviewed the transcripts, and coded the data. Throughout this study, I worked closely
with colleagues and parents who have provided continuous feedback regarding the
selected procedures and interview questions.
5. **Researcher’s biases:** Clarifying the researcher’s assumptions, beliefs, and theoretical orientation is an essential aspect of internal validity. I am undoubtedly committed to improving the quality of educational services for students who have intellectual disabilities. My conjecture is supported in the literature, with significant evidence that supports the practice of integrating students with intellectual disabilities into general-education classes, yet, the practice remains uncommon. My biases were tempered through the range and open-endedness of the interview questions, the collaborative team interview, and videotaped observations and interactions. I invited an objective observer to monitor the focus group interview. She is the parent of a child with Down syndrome, and a professional who serves on the board of directors for the local ARC. I also invited other professionals to observe and code data from the videotapes during the analysis phase of the study.

Throughout the study, I compared various assumptions and procedures to identify a common terrain on which to build (Yin, 1994). The design of the study included rigor. My critical presence in every aspect of the study—triangulation of participants’ perceptions, interpretations, and continuous verification—contributed to the quality of this study.

**Generalizability**

The extent to which the findings of this study can be applied to other situations determines how generalizable the results are. Lincoln and Guba (1981) pointed out that even to discuss the issue of generalizability, the study must first be internally valid. On the other hand, the study can go too far in controlling for factors, which might lead to...
findings that can be generalized only to other highly controlled, largely artificial situations. Thus, the question for this study was, "Is it possible to generalize the findings from the three cases selected?" The predetermined questions and specific procedures for interviews, observations, and analysis enhance the generalizability of findings in the traditional sense (Burlingame & Geske, 1979; Firestone & Herriott, 1984; James, 1981; Miles & Huberman, 1994; Schofield, 1990; Yin, 1994).

Erickson (1986) points out that generalizable knowledge is an inappropriate goal for interpretive research. In attending to the particular, concrete universals are discovered. "The search is not for abstract universals arrived at by statistical generalizations from a sample to a population," he writes, "but for concrete universals arrived at by studying a specific case in great detail and then comparing it with other cases studied in great detail" (p. 30). The general lies in the particular; that is, what we learn in a particular situation we can transfer or generalize to similar situations subsequently encountered. This study provides the reader with three case studies where there were some common characteristics, yet each student's learning experiences and the experiences of their parents, team members, and classmates were unique. Describing in detail and comparing the three students' experiences and the experiences of personnel and classmates provided detailed description to the study's context to enable readers to compare the "fit" with their situations.

Generalization can be regarded not only as going beyond the information given (Bruner, 1973), but also as transferring what has been learned from one situation or task to another. What generalizes is what one learns, and for the purposes of this study, these can be regarded as (1) skills, (2) images, and (3) ideas. In Brunerian terms (Bruner,
1961), they correspond to the enactive, the iconic, and the symbolic aspects of human cognition (Eisner, 1991, p. 199).

The term *skill* in this context relates to my own ability to write about what was observed and perceived. *Images* are constructed from the words whose form and content have the ability to generate parameters for seeing and classifying (Neisser, 1976). The stories I wrote are an expression of their generalizing capacity. It is these generalizing capacities that lead the reader to look for certain qualities in an educational program for a student with intellectual disabilities in general education settings. Although skills and images are two of the modes that enable us to generalize, they are not the ones we usually think about first. A generalization is usually thought of as a statement about a condition that exists, some claim or proposition that purports to be true. This study allows the reader to create new ideas about the benefits of integrating students with intellectual disabilities in general-education classes in a middle school. Describing the experiences of the three students in this inquiry allows the reader to make predictions or at least have expectations about future practices regarding students with disabilities.

To enhance the possibility of generalizing this study, the following strategies were used:

1. *Rich, thick description:* This study describes in detail three students' educational experiences in middle school. The focus group with the students' parents begins the descriptive process by providing the reader with information about the parents' experiences based on their responses to the questions. The focus group was videotaped and analyzed. The group members' interactions with each other and their responses to
my questions provide the reader with an understanding of how the students’ educational experiences are perceived by the parents.

The semi-structured interviews conducted with the school teams and the classmates provided me with a wealth of information that helped me to understand their perceptions. The information gained through my direct observations and through the various documents I found in the school records provided me with additional data that proved to be quite useful during analysis.

Together, this information provides the reader with thick, rich descriptions to determine how closely their situations match other research situations, and hence, whether findings can be transferred (Merriam, 1998).

2. Typicality or modal category: This describes how typical the situation is compared to others in the same class, so that others can make comparisons with their own situation (LeCompte & Priessle, 1993). This study included three students who share the same diagnosis of Down syndrome and the label of mental retardation. The students all attended their neighborhood middle schools, and spent time in general-education classes during their school day. The three cases represented the phenomenon of inclusive education in typical school settings. I made comparisons among the three student’s situations. The reader can draw conclusions that would lead to a comprehensive understanding of each students’ experiences and the aspects that transfer to their own experiences.

3. Multi-site designs: The selection of the three students in the study was based on a purposeful sample. The purposeful sampling procedure is described in detail in this chapter. The selection is, to a degree, representative of students who have the diagnosis
of Down syndrome. Although the three students share the same label, they each have very different levels of academic and social abilities. The three school districts where the students are enrolled are not as diverse as I had hoped. I was not successful in locating a student in an urban setting who was fully included. The three students who were selected, however, are in schools that are representative of many districts in the state where the study was conducted. The use of three different cases in this study provides the reader with opportunities for comparison. The results can be applied to a greater range of other situations, thus enhancing external validity.

Ethical Considerations

“If there were simple rules to apply, we could be easily taught to follow them and in so doing to feel confident that we were doing the right thing all of the time.” (Eisner, 1991, p. 213). The principles, concepts, and considerations relevant to qualitative ethical research include the following:

1. *Informed consent:* Each of the parents who volunteered to participate in this study signed a consent form after lengthy discussion with me, reading the document that was approved by Andrews University Human Subject Review Board, and discussing it with each other and then their sons. The notion of *informed consent* implies that researchers are able to anticipate the events that will emerge in the field about which those to be observed and interviewed are to be informed. Not knowing what the findings would be, the participants were provided with as much information about the study as possible. The principals from each of the three middle schools received a letter
describing the study while seeking permission to access the students, educators, and classmates. All three principals responded by telephone within 2 weeks of receiving the letter. Permission was enthusiastically granted in all three cases.

Eisner (1991) poses a question to which I gave considerable thought because the students with Down syndrome are considered mentally retarded: *Is a person and or group adequately informed if they do not have the technical sophistication or expertise to raise questions that someone more sophisticated would raise?* I had an ethical responsibility to serve in a dual role: first, as a researcher with a project aimed at completing a study that would ultimately contribute to the literature that supported the integration of students with intellectual disabilities in general-education classes; second, as an advocate for the students, parents, and practitioners, raising questions that I knew should be raised in order to make a competent assessment of the risks. Before each observation was conducted, I met with the students to introduce myself and the technician who would be assisting me with the videotaping. Although the students each signed a consent form at the onset of this study, it was important for the students to know that we would be in the classrooms and that we would minimize any disruption we might cause. The student was given the opportunity to ask questions before we began the observation. Each of the boys wanted to participate in the study and was happy to have us there.

2. *Confidentiality:* The consent forms signed by the participants includes the following information: "Confidentiality and anonymity will be maintained throughout the study." Only first names are used during the interviews. Personnel are referred to by their first names. The school districts where the students are enrolled are not identified in the study. The students' names were changed in all publications of the study.

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Videotapes, audiotapes, documents, and related data will be used only with the consent of the participants. The privacy of all participants was maintained throughout. I have not discussed the school districts, their personnel, the families, or the individual students themselves with any person not involved in the study. I assured the families and participants that these standards were adhered to by the technician, the reliability coders, and the independent observers. As Stake (1994) observed, "qualitative researchers are guests in the private spaces of the world. Their manners should be good and their code of ethics strict" (p. #).

3. Autonomy: The people involved in the study must be respected and at all times. Any person involved in this study was provided the opportunity to "opt out" at any point in time. Teachers or school administrators could have decided that the procedures were too invasive, or that the time selected by me and school personnel was not available and could not be rescheduled. I was well aware of the unpredictability that permeates schools daily. Being flexible and positive with the participants aided in making data collection successful.

4. Personal identity: The identity of each participant was respected throughout the study. I valued each person who gave his or her time and energy to participate in the completion of this study. Maintaining every person's dignity throughout the study was a foremost consideration. I adhered to the guidelines described and remained conscientious to ensure that the study was conducted and disseminated in an ethical manner.

The world of qualitative inquiry includes multiple constructions of reality where the researcher is the primary instrument of data collection and analysis, and where understanding and meaning are of paramount importance (Merriam, 1998). The
structures and approaches described in this section lead me to believe that adequate safeguards for the passage from writer to reader (Stake, 1994) were in place. The completion of this study is the ultimate determinant.
CHAPTER 4

JOE

Who Is Joe?

Joe was born on March 10, 1986. He is the oldest of four children, three boys and one girl. When he was born, his parents thought that everything was fine until several hours later. Joe’s dad noticed the attention that his newborn son was receiving from the doctor. Immediately after the examination, the doctor invited Jay into the hallway to speak privately. “We walked to a supply room behind the nurses station where he informed me they had strong reason to believe that Joe had Down syndrome.” They found the doctor to be compassionate and supportive.

Jay and Sally are college graduates. Jay is a financial consultant while Sally is home with the children. They both understood that their son had a disability when the news was shared; however, neither of them knew a person with Down syndrome.

Immediately after learning of their son’s diagnosis, both parents began reading as much literature about Down syndrome as they could get their hands on. They networked with other parents and enrolled Joe in early-intervention services. Joe received services in his home as an infant. He was evaluated by the team of professionals from the “Birth to Three” program and was enrolled in a program where he and his mom or dad would join other parents and professionals in small-group instruction. Joe made remarkable
progress developmentally. He had no medical complications and was only slightly delayed in achieving motor and cognitive milestones during his first 2 years.

By the time Joe was 2, he had a brother. His parents became active with the Down Syndrome Congress, and continued their active participation in developing a strong network with other parents of children with Down syndrome. This network of parents became a force of support when other families learned of the news that they too were parents of a child with Down syndrome. Together, this group of parents educated themselves by inviting speakers to their meetings. They shared information with each other and became familiar with the language associated with disabilities, special education, and the like.

When Joe turned 4, he was enrolled in the public school’s preschool program and became a big brother again. He attended the program three afternoons a week and continued to make good progress. His strengths were in the motor and social skill areas, while his challenges were in communication (articulation). He was a happy little guy who became very popular among the teachers and therapists in the program. There was a positive relationship between the parents and the professionals.

At about this same time, Joe’s parents decided that they wanted their son to attend his neighborhood school, and the following year, be enrolled in the kindergarten class he would attend if he did not have a disability. Joe’s dad made an appointment with the principal of the school to inform her of their intention. The principal was not receptive to Jay’s request. She said, “We have special-education services in another building, and he couldn’t possibly ride the regular bus!” Her response caught Jay off guard. Up until this point, the parents had not experienced any resistance to their wishes. The meeting was a
short one. Jay immediately contacted an educational consultant and an attorney to find out what he needed to do.

The attorney recommended that an independent evaluation be conducted. With continued resistance on the part of the principal, the evaluation was completed and a meeting to discuss the parents’ request and the recommendations of the evaluator was scheduled. The meeting was attended by the district special-education administrator, along with teachers, therapists, Joe’s parents, and the independent evaluator. The recommendation was made for Joe to attend kindergarten in his neighborhood school. The district personnel knew that Joe’s parents were serious about their intent and hesitantly agreed to enroll him in kindergarten.

Between the time that the meeting occurred and the day that Joe would start kindergarten, the resistant principal retired and a new principal greeted Joe on his first day with open arms and a promise to make it work! Joe’s parents were more than grateful to meet this new administrator.

Joe’s kindergarten year included every experience that every other student in his class enjoyed. He also received direct services for speech, occupational therapy, and special-education instruction. The speech therapist would work with him in the classroom and serve him in her therapy room for articulation and oral-motor intervention. The special-education teacher would collaborate with the kindergarten teacher, adapting activities and modifying instruction along the way.

Joe continued to attend his neighborhood school through Grade 5. During this time, he rode the same bus with his brothers and friends from the neighborhood. He participated in a variety of extracurricular and sports activities and became a Boy Scout.
with his brothers. The school received an award during this time for providing Joe with an exemplary inclusive program. His picture was in the paper and the school received very positive press for leading the way for other students.

Joe continued to receive special-education services while he was enrolled in the regular classes. He was "pulled out" of class for direct reading, math instruction, and for speech. He learned to decode words, read sight words, complete basic math problems, and cooperate with classmates in a wide range of learning opportunities. He never missed a field trip or was excluded from any activity that was made available to his classmates.

Joe’s social abilities have always been his strength. He is a very happy person who modulates his behavior in appropriate ways. He has never presented the school team with behavioral challenges that required any formal intervention. However, he learned how to use his charm to manipulate situations in his favor.

When Joe was leaving the elementary school to move to the middle school, there was a ceremony that was attended by the students and parents from his class. Since he was the first student in the district to "be included" in regular education classes, his father asked for an opportunity to speak to the group. He told them that he was grateful for the opportunity to have Joe in his neighborhood school and that the strength of his program came from the people who surrounded him. He then asked Joe if there was anything he would like to add. Joe got right up to the microphone and said, "Thanks guys," raising his arms in victory! Reportedly, there was not a dry eye in the room.

Before Joe was enrolled in the middle school, his dad again made an appointment with the principal who welcomed him with open arms. She indicated to him that there
were already students at the middle school with special-education needs. She set up a meeting for Joe and Sally to meet the team that would teach their son and to design a program that would meet their expectations and Joe’s learning needs.

Joe entered middle school along with the students he knew from his elementary school. The environment was much bigger, there were many new students, and there was a very different schedule to follow. There was a para-professional assigned to support Joe in the classes where he would need help. He adjusted quite easily to the new environment, never hesitating to introduce himself or participate in social opportunities.

When Joe is not in school, he enjoys playing with his brothers and other children outside. He has learned how to ski and play a variety of team sports. He attends religious education classes and the parks and recreation programs with typical peers. Joe graduated from eighth grade and was then enrolled in his local high school.

**Joe’s Team**

The team members whose names appear on the first page of Joe’s IEP include the following: The school administrator (principal), both parents, the special-education teacher, school psychologist, speech/language therapist, guidance counselor, nurse, Department of Mental Retardation case manager (an outside state agency that provides services to individuals with mental retardation), an inclusion consultant, the para-professional, and the PE teacher (representing the role of a regular education teacher).

These were the people who developed the educational program for Joe in middle school and were responsible for its implementation. When I initially approached Joe’s parents to consider their participation in this study, it was explained that there would be
interviews and observations that involved members of Joe’s team. Joe’s parents were enthusiastic about the possibility of sharing his success with others. His dad said, “Joe has a fantastic team of people who would be happy to work with you.”

After the parents participated in the focus group, a schedule of observations and interviews was developed. The principal of the middle school arranged for the special-education teacher to be the contact person for me to access Joe’s team. One week prior to the date of the observation and team interview, I called the special-education teacher to confirm the date and expectations. It was my intent to meet with teams during their planning time so as not to interrupt their schedules to any great extent. I asked, “What time does his team meet?” The special-education teacher responded with “What team do you mean?” I then explained that I needed to have members of Joe’s team come together to participate in an interview, answering questions about their experiences with Joe. She said that they did not have any time when the general-education teachers meet with the special-education staff to discuss Joe’s program. She went on to say that she meets with the aide on a regular basis to plan his participation in activities, but that there is no planning time with the teachers from the general-education classes. This was a surprise. I had assumed that some mechanism for planning was in place and that such planning included members of his Planning and Placement Team (PPT). After further explanation about this study, the special-education teacher assured me that there would be representation from the general-education classes at the interview.

On the day of the interview, the room that was initially reserved for me to meet with Joe’s team became unavailable. With limited time and limited space, which were an indication of the overcrowded conditions that existed in the school, we found ourselves in
the special-education classroom where students with disabilities receive instruction from the special-education teacher. There was no wall space to hang the paper that was intended for the group to have a visual focus. Instead, we sat at a table where the questions were in front of us. The participants included the following:

The special-education teacher has been teaching in the school system for 10 years. She had worked at the middle school for 5 of those years. She was also the parent of an 11-year-old with Down syndrome. This teacher worked directly with Joe in her room two to three times per week. She designed the instruction for him in both the regular- and special-education environments. She was primarily responsible for monitoring the IEP.

The Physical Education teacher was an energetic young woman who provided enthusiasm and shared a wonderful story during the interview. She stated that she works with Joe in both the regular PE class and the Adaptive PE class. She has known Joe for 2 years and found him to be “a joy to work with.”

Joe’s para-professional was a woman who works in the school and has a son who is a student in the building. She spent all of her day working with or near Joe. She is responsible for making sure that Joe was where he was supposed to be and participating in the classes to the greatest extent possible. She said she had not received any training to work with Joe, other than “on the job.” She liked the work she does, but said that “pay day was the most embarrassing day of the week.”

The Speech Therapist was a woman who has been in the system for many years. She saw Joe in her therapy room as well as in a variety of classes. She collaborated with the para-professional in designing strategies to improve Joe’s articulation, pragmatic skills, and breath control.
According to The Merriam-Webster Dictionary (1998), a team is defined as "a number of persons associated in work or an activity." "Teamwork" is defined as "work done by several associates with each doing a part but all subordinating personal prominence to the efficiency of the whole." To that end, Joe has a team of enthusiastic members who had very positive stories to share and have enjoyed his many successes as a student at the middle school. During the observations and interviews, it was apparent that this group of people interacts frequently but not on a scheduled basis or in a manner that leads to well-planned instruction. For example, Joe has been visiting the high school for several weeks each Friday, in an attempt to increase his comfort level with the new school and to determine which classes would best meet his individual learning needs. One of the interview questions focused on the future. The team members began discussing his current schedule of high-school visits. It was the first that the Speech Therapist knew of these visits.

Evidence of limited team planning played itself out in the regular-education academic classes. The Social Studies teacher did not play a role in deciding what Joe was responsible for learning. He participates in the class on a limited basis, and the decisions were left to the special-education teacher and the aide. The aide had the option of deciding whether or not Joe would stay in the classroom during certain activities. During my observation, he left the class a few minutes before the class was over. It was not clear what the reason for leaving was. When clarification was sought, the aide said that the class would be reviewing homework that Joe was not going to do, so they headed out early for the next class.
Communication between school personnel and Joe’s parents was frequent. The special-education teacher maintains close communication with Joe’s parents. During the focus group, Joe’s mother said that both she and her husband go to all the meetings together. “If one of us can’t make it, we reschedule the meeting so that both of us are always there.”

Joe’s team can be described as committed, caring, and compassionate. There were people named on the IEP who did not have defined roles, including the “inclusion consultant,” the school psychologist, guidance personnel, the nurse, and DMR case manager. People missing from the planning process included the foods teacher, the Social Studies teacher, and Science teacher. Although Joe is integrated into regular education classes for portions of his school day, the expectation that the general-education teachers have responsibility for his learning goals and objectives is lacking.

Joe’s Educational Program

The Individualized Education Plan

The IEP, as required by IDEA (1997), was developed to define the individual needs of the students, the educational services necessary to implement the plan, and the day-to-day provision for delivering the specially designed instruction. This was intended to be a planning document which shaped and guided the delivery of special-education services (Rainforth & York-Barr, 1997). Joe’s IEP reflected a planning meeting that occurred in April 2001. His parents actively participated in the planning process to the extent where they were asked, “What do you want?”
In addition to his parents, Joe’s planning team included several professionals and his para-professional. The team made the following recommendations:

1. He will continue to participate in Adaptive PE once a week.
2. He will participate in speech group and receive individual services.
3. He will receive counseling one time per week.
4. He will go to the learning center one period per day for skill reinforcement at the beginning of the day.
5. He will receive extended school-year services in the summer.
6. He will receive the support of a para-professional in mainstream courses.

Joe’s present levels of educational performance were described in terms of his strengths and concerns or needs. Strengths included good work behaviors, well organized, sociable, works well in a group, rules-driven, responsible for himself, life skills, vocational skills, fine motor skills, and gross motor skills. He was also described as a hard worker. Areas of concern included articulation, motor planning, working with money, subtraction, telling time.

The PPT minutes describe the testing that was completed as part of what is referred to as a triennial review. That is, every 3 years, assessments are completed to measure progress and determine whether or not a student continues to qualify for special-education services. The testing that was completed for Joe included achievement testing, a speech evaluation, and a review of progress to date as they related to his IEP. Joe has a slight hearing loss which continued to be evaluated and monitored by his team. He wears a hearing aide and did not need any other accommodations for this. The plan included a
statement about homework, modifications to the curriculum, and scheduled meetings with Joe's parents.

The learning goals and objectives were delineated in the document. The first goal, identified as academic, identified word attack skills and articulation. It states that he will be given direct instruction by a special-education teacher and reinforced by staff. The objectives detail the approach that was used (pronounce words in a variety of selected reading passages). There were four objectives for reading instruction. The second learning goal addressed spelling skills. The goals were all written in a manner that described instruction from a special educator and reinforced by staff. The third goal addressed writing skills; the fourth, reading comprehension; and the fifth, writing mechanics.

The sixth goal addressed math skills (money and time), the seventh addresses computation and measurement. The objectives delineate coin combinations and opportunities to instruct him in learning measurement. The eighth goal area addressed the development of vocational skills through participation in unified arts classes. The ninth goal addressed speech services, which were scheduled to occur in a small group and individually. The last goals addressed his participation in a special-education PE class.

The last part of the IEP addressed the hours of service. He received 18.5 hours of special-education instruction, 3.5 hours of related services (speech and adaptive PE), 10.5 hours of regular education participation, with a total of a 32.5 hours per school week.

The last page of the IEP identified the various modifications and adaptations that needed to occur in regular education activities. The boxes checked on this page indicated that he received modified work, had access to a computer, had modified tests and

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quizzes, modified grading, support for organizational skills, environmental considerations (preferential seating), and a range of instructional strategies. Joe's parents were in agreement with this plan.

Consideration of Best Practices

Williams, et al. (1990) identified nine “best educational practices for students with severe disabilities.” These best practices were used as a guide in analyzing the students’ educational programs.

1. Age-appropriate placement in local schools: Joe is in the school he would have attended if he did not have a disability.

2. Integrated delivery of services: Because the related services are delivered in separate settings, and there was no scheduled time for collaborative planning, this practice was not in place. One of the work samples that I reviewed was the outcome of a cooperative-learning project that Joe completed with a group of peers in his social studies class. This was the closest example of integrated services, given that there had to be some aspect of planning and implementation for this to be completed.

Joe’s work samples included a product from a cooperative work group that Joe participated in with three other boys. This project was an assignment from his social studies class. The students developed a newspaper they called “The Boston Times.” This newspaper included articles written by each of the boys relevant to the early 1700s, highlighting “The Boston Tea Party” and “Samuel Adams.” Joe’s role was to write a restaurant review for an Old English Tavern. His article included a recipe for hot cakes and a picture. On the last page of the paper is a picture of Joe and his classmates and the
roles they played in completing the project. The questions were written and there were spaces for Joe to write the answers. He completed the activity, printing the correct responses with a pencil. His printing is legible, making it easy to read. He was able to fill in the blanks with the correct responses. He did require some assistance with spelling names correctly.

3. Social integration: Joe’s social integration is a strength in the program. His educational program provided him with opportunities to participate in a wide range of educational activities that occurred in regular-education classes. During the observation, he actively participated in regular-education classes. He required some assistance; however, there were no instances where his needs would have been considered to be extraordinary. He did seek the assistance of peers after being prompted (by the para-professional) to ask for help from a classmate.

4. Transition planning: The advanced planning of major moves, that is, moves to a new school, or to a new program, is a practice that this team demonstrated in that Joe was already visiting the high school he was planning to attend the following year. These visits occurred as a result of the parents’ request.

5. Community-based training: The intent of this practice is to provide students with opportunities to learn skills in their natural environments. Joe did participate in community-based learning activities. When they occurred, the activities included only students with disabilities.

6. Curricular expectations: There was a lack of systematic planning and longitudinal monitoring of Joe’s educational services. Joe’s work samples were analyzed and showed indications of modifications and adaptations that were made so that he could
participate in regular education activities. The richest example of classroom participation
and playing a valued role in the class was evidenced by the cooperative-learning activity
that Joe engaged in with three other boys from his class. The "Boston Times" project
provided Joe with opportunities to work with typical peers over an extended period of
time. However, the fact that there was no mechanism for collaborative planning created
a gap between the expectations for Joe and the delivery of instruction in the classroom. It
appeared as though Joe's instruction was not the responsibility of the regular education
teachers. Although not specifically stated by any team member, members of the team alluded to the fact that they did not want to burden the regular-education teachers with
planning and delivering instruction. That was the special educator's job. Unfortunately,
this approach led to a fragmentation in the delivery of instruction and the level of
participation for Joe.

In the less-structured classes, Joe did extremely well. In the more-structured
classes or formal academic classes (social studies), he relied more heavily on the aide to
direct his activities. As stated earlier, there was no mechanism for the regular education
teachers to plan his instruction with the aide or special-education teacher. The special-
education teacher did not spend any time with Joe in the regular classes. She primarily
instructed him in a separate setting (her classroom) or she directed the para professional
in delivering his instruction.

The overall strengths in Joe's program were found in the regular-education
classrooms where he had the opportunity to engage in conversation with peers,
demonstrate skills that he had learned, and integrate information from the rich aspects of
the middle-school environments.
7. Systematic data-based instruction: There were no (systematic) data for me to review relevant to the goals and objectives in Joe's plan. The data that were shared were work samples and test results. The instruction lacked appropriate planning; there was no data system and the selected activities appeared haphazard to me.

8. Home-school partnership: Joe's parents established clear expectations early on in his education. They made their vision clear to Joe's team and there was evidence of a strong partnership. There was a daily notebook with notes from either the special-education teacher or the para-professional, describing homework, upcoming events, or anything that they felt the parents should know. Oftentimes, one of Joe's parents would write back, indicating that they had gotten their information. Joe's parents also had a visible presence in the school. When Joe's mother arrived at the school on the day of my observation, she entered the building, greeting teachers with familiarity.

9. Systematic program evaluation: The IEP process builds in a schedule for evaluation of a student's progress on a quarterly basis. The IEP had data that were entered into the appropriate boxes. Joe's team also evaluated him as part of the triennial review, providing data relevant to his academic skills and communication abilities. I asked the special-education teacher if there was a data system in place that would provide me with raw data to review. There was not.

Summary

The level of satisfaction that was shared by this team exceeded my expectations. Their perception of Joe's successes and the fact that they had no recommendations for improving or changing the program led me to believe that the team members lacked
experience with the implementation of best practices, but more importantly, did not have a systematic plan in place that would provide all of the students with special needs the same opportunities that were afforded Joe. It was challenging for me to observe Joe in the rich integrated settings and then observe him with other students who had very significant learning needs in segregated settings. It seemed as though the waters parted for Joe to be included in regular-education classes as a result of his parent’s advocacy. The waters closed quickly behind him for any other student with significant disabilities. There was a significant amount of segregation in this school, in spite of the success that Joe experienced. Joe was more socially appropriate and independent in integrated settings. When Joe visited the segregated classrooms, he appeared to need more help and behaved differently.

**A Day in the Life of Joe**

The following is a story that was written using the data collected relevant to Joe’s educational experience. It is a composition created for the reader to understand some of the highlights that occurred in Joe’s life during this study.

“Joe, the bus is going to be here any minute! If you’re late, you know you will have to stay for detention and we can’t have that happen today!” Joe made his way down the stairs half asleep. While he was finishing breakfast, his mother reminded him “to take your woodworking project back to school to finish it. It is going to be a wonderful birdhouse when it is finished.”

Joe grabbed his backpack, project, and lunch. The bus arrives at the stop just in time for him to hop on the bus with his brothers and sit in the first seat. “Hey Joe,” “S’up
Joe," the students said. The bus arrived at school 15 minutes later. It was filled with students anxious to begin another week at County Middle School.

After going to his locker to place his lunch and backpack, Joe made his way to his first class. The classroom was filled with students, all excited about the recent chapter in "Harry Potter" that they were assigned. "I've read the whole thing already," said Sherry, who then turned to Joe and asked, "Did you listen to the chapter last night?" Joe responded, "I did and read it too with my dad." "Wasn't is fun?" she said. "I like Harry Potter," said Joe. By that time, the classroom teacher and the aide assigned to support Joe entered the room. The students all took their seats and waited for instructions. The students were directed to participate in cooperative learning groups and answer questions that were delivered to each group. Joe's group included three other students. The aide assigned to assist Joe worked briefly with his group and then moved about the room encouraging his classmates.

At the end of Language Arts, Joe exited the classroom and proceeded to his next class. On his way, he stopped to get his birdhouse from his locker. His aide had gone a different route, stopping at the copy machine to run off copies of his schedule for the week. Joe had trouble getting his locker opened. The student using the locker next to him offered to help. Joe allowed him to assist and then responded by saying "Thanks."

Joe arrived at his class with the birdhouse. Joe went over to the selections of paint. His aide was there to assist him in pouring the correct amount into the smaller can. Joe selected two colors, one for the roof and one for the sides. He returned to his seat and started to paint. The aide left the room. During the class, Joe was focused on his task. He painted diligently throughout the entire class. At one point, his classmates became
rather loud while the teacher was in the hallway talking to the principal. Joe never stopped working. He finished the sides and decided to leave the roof until the next day. The birdhouse would remain in the classroom to dry overnight.

The next class scheduled was PE. Joe made his way to the gym amidst a group of familiar students. Joe greeted many friends along the route. There were a lot of high-fives, and “hey Joe’s.” Once in the gymnasium, there were 19 other students waiting for the teacher. On this particular day, the students were taking turns climbing and bouldering with ropes on a wall that was set up to teach students about balance, rock climbing, and safety. Joe stood with the other students while the teacher read the instruction and safety rules. He was attentive for the majority of the time. As the students lined up to take turns, Joe moved towards the back of the line and waited until everyone else was in line. He never actually stood in line. He watched every student go up and make his or her way down the ropes. Some students were quite efficient in their moves, while others took a very long time. All of the students were supportive of each other. As each student made their way back to the floor, the students gave each other a round of applause.

The last student landed on the floor. While the classmates were cheering, Joe stepped forward and said “My turn.” The teacher looked surprised. She looked at the aide as if to say “Shall I let him?” The aide nodded and Joe proceeded up the ropes. Everyone in the class stopped and watched him. They were extremely quiet. When Joe arrived at the top, he looked down and became very nervous. He said, “I need help.” The teacher started to instruct him and all the students started saying, “C’mon Joe, you can do it.” Joe started to move slowly. He moved one foot, then the next. The students continued “Go Joey,” “Go Joey,” He gained confidence as he started to make his way
down the ropes. He gradually made his way back to the floor amidst loud cheering and clapping. Joe jumped away from the ropes with his hands in the air saying, "I did it!"

The ladies were in tears; the boys were slapping him on the back.

Joe made his way to the cafeteria where there was a table filled with students. Joe joined the group, which has become part of his daily routine. At the table were three boys who all participated in Boy Scouts with him. "Are all you guys going tonight?" asked Bryan. George responded, "I am." Joe said, "My dad is bringing me and my brothers." The other students at the table asked what was happening that night. "We have our awards banquet for Boy Scouts tonight," said George. "We have all worked hard on our badges this year and tonight is the night that we get our badges." The boys went on to discuss a variety of topics, never touching on any aspect of their academic careers.

When the first wave of students left the cafeteria, Joe exited with his friends. He encountered one of his brothers in the hallway, making physical contact as if to hit him in a playful manner. As a sixth grader, the brother’s response was minimal.

Joe entered the science lab. The lab consisted of high black tables with stations for six students to gather around. Joe was at the table closest to the door. His aide met him in the room. She asked him for some papers and gave him a paper. The teacher turned off the lights and proceeded to review overheads depicting the parts of a cell. The paper that was handed to Joe had a picture of a cell with less detail than the overhead. Fifteen minutes into the class, four of the students had their heads on the tables as the lecture approach to instruction continued. Joe’s head was down. The aide noticed him
slouching and approached him with a whisper. He put his head up and then followed her out the door.

Joe and his aide went to the Resource Room where he sat at a table by himself waiting for the aide to put her belongings down at her desk. She asked Joe to take his paper out and color in the cell. As she sat at her small desk, the special-education teacher entered the room. “Hi Joe,” she said. “What are you doing here?” Before Joe could answer, the aide said, “He was just about asleep in Science, so I thought he could come down here and work. He wasn’t getting anything out of being there.” The special-education teacher responded, “I just need to get my paperwork for the Student Assistance Meeting (SAM) this afternoon.” “Is he going to Art?” “Yes,” said the aide. Joe colored his cell and then put his head down for the 3 remaining minutes of the class time. By this time, three other students had entered the room and were waiting for the special-education teacher to give them an oral test.

Joe exited the room and joined a number of students heading in the same direction towards the stairs. He made his way to the cultural arts wing of the building and into the art room. There were two girls sitting in the room talking. Joe sat next to them. They greeted him and then went on with their conversation. Joe looked at them admiringly, but was then distracted by the large group of students who entered the room. The teacher entered the classroom as well. He had several large pieces of paper with pictures and students’ names on them. One belonged to Joe. Once Joe got his picture, he started to work on it. The aide then entered the room and checked to make sure Joe had all of the materials he needed. She moved about the room helping Joe’s classmates with various aspects of their projects. Joe worked independently throughout the class.
When the class ended, Joe returned to the resource room where he reviewed his homework assignments, his schedule, and gathered his belongings that he had left there before Art. There were four other students with significant disabilities in the classroom by this time. Two of the students had aides with them. During the last 15 minutes of school, Joe sat at the table and started his homework. He said, “I have to finish before tonight. We are going to Boy Scouts tonight.”

While Joe worked, the three aides socialized and the four students waited for their special transportation. The aides were notified that the bus had arrived, and the students left. Joe remained in the room until he heard the bell for dismissal. He exited the building with his peers.

Joe’s mother picked him and his brothers up that day. They left the school parking lot and headed to the mall to buy shoes for the banquet that evening. Both Joe and his brother were in need of new shoes. Joe’s little sister was along for the ride, while his youngest brother made his way home from the elementary school independently.

Joe demonstrated great safety skills in the parking lot, holding his little sister’s hand as they made their way into the mall. They identified a store that would have the appropriate shoes for the evening event. Joe selected the shoes he wanted to try on. The store clerk interacted with each boy individually, looking occasionally at Joe’s mom to clarify or interpret what Joe was saying. The purchases were made and the siblings followed their mom out to the car.

At home, each boy has chores to complete on a daily basis. Since Joe has such difficulty getting up in the morning, his chores have yet to be done. The first job to be completed was his bed. Joe shook the covers, smoothed them out, and threw the pillow
to the top of the bed. He gathered his laundry and brought it down to the laundry room, placing it in a basket with other clothes. In the kitchen, he opened the dishwasher and put away all of the dishes. He used a step stool to reach high cabinets, placing each glass on the shelf carefully. He handled the knives with skill, and placed all of the silverware in their appropriate location in the drawer.

Once his chores were done, Joe returned to his homework. He sat at the kitchen table working, while a flurry of activity occurred around him. His brothers were in the kitchen getting themselves an after-school snack, talking about the banquet that night and their accomplishments. Joe stayed with his homework until it was completed. In the meantime, his brothers had left the house and were on the front lawn having a catch. There were other kids from the neighborhood gathering in front as well. Joe joined the group with his baseball mitt in hand. Joe caught his brother's fast throw, returning a faster ball to him. The boys played for a while, then sat on the front steps talking. Joe listened more than he spoke. He laughed at appropriate times, and agreed with much of what was said.

By this time of the day, the members of Joe's family were getting ready for the banquet. Joe got dressed in his uniform. He put on his new shoes and some great-smelling aftershave. He was the first one ready. As each member of the family made their way to the kitchen area, Joe's dad arrived home from work just in time to load the family into the van and head for the banquet.

The banquet room was filled with linen-covered tables, folding chairs, and a podium at the front of the room. Joe's family entered the room and made their way to a
table that would accommodate the six members of the family. All three boys wore their clean, pressed uniforms.

All of the participants arrived and ate a buffet dinner. After dessert, the scout master initiated the awards portion of the evening. He gave out badges to a variety of boys for a variety of accomplishments. Joe received a badge and each of his brothers received badges as well. As the last badges were given out, the scout master said that there was one more award that is given annually at this banquet. It is the award where you as a troop identify a fellow scout who has demonstrated exemplary scouting during this past year and serves as a role model to us all. This year, the award went to Joe. He was selected by his peers as the recipient for this award. As Joe went forward to accept his award, the entire banquet hall crowd rose to their feet, giving him a standing ovation as he received the award.

Joe's parents were honored and quite surprised. It was a very proud day for the entire family. When they arrived home, Joe headed straight up to his room and into his bed. Joe went to sleep.

Themes and Impressions

"Joe is a very dynamic young man," said his dad as he introduced himself and his wife during the focus group interview. "Social" and "satisfied" were the codes that emerged early in the analysis of Joe's data. Joe's mother shared a story about his sense of humor when he had his shoes on the wrong feet. He crossed his feet and said, "No they're not!"
Joe's parents became educated about Down syndrome as soon as they learned of his diagnosis. The help that they sought and received through the Connecticut Down Syndrome Congress, from specialists in the field of medicine and education, as well as from other parents, led them to a vision and commitment to educate Joe in his neighborhood school with typical peers. "We are dead serious about this," said Sally during the focus group interview. From the beginning, they were clear that they wanted a high level of social relationships while, at the same time, an opportunity to learn life skills that he will use in the future.

The initial resistance that Joe's parents experienced from the elementary school principal when they approached her with their dream was the first and only stumbling block they felt they encountered. On his first day of kindergarten, a new principal with an open attitude and welcoming words greeted Joe's parents. As Joe made his way through elementary school, he developed relationships with the children in the neighborhood and moved from grade to grade with his same age peers. One of the students who participated in the friends' interview said that she had known Joe for 8 years. Themes of friendship and social learning opportunities became the landscape of Joe's education.

"Every day is amazing," said Joe's PE teacher when asked to share a story. She described Joe's experience in her class where he was motivated to succeed as his classmates cheered for him. During the observation, there were numerous occasions where Joe made social connections with other students. I observed rich social interactions when his classmates provided him with assistance and when the adults were not involved in the interactions. A fire drill, in most instances, might be considered a
routine exercise at a middle school. For Joe, it was a social learning opportunity where he observed age-appropriate bantering and numerous nonverbal gestures that he easily understood and replicated on his way into the building. Middle-school students have a means of communicating with each other that circumvents the supervisory eyes of the adults in that environment. Joe is part of that communication, evidenced by eye contact, smiles, grunts, and slight hits that occurred as the students re-entered the building.

Professional insight and growth emerged as themes during the focus-group interview and continued through the team interview and observations. Although Joe was not the first student in his middle school to attend regular-education classes, according to his parents, he was one of the first to be enrolled in regular classes during elementary school. The stories shared by his parents illustrated the effect he had on the teachers and special-education support personnel. "You don’t know who is coming to the table each time, so you have to raise people to the greatest expectations," said Sally. As the data were analyzed, the themes of satisfaction and relationships continued to evolve.

The theme of satisfaction was most evident when I asked the team what they would change. "Nothing!" exclaimed Joe’s special-education teacher. "He’s really lucky." "He’s really independent." "His parents are very happy." Joe’s parents and the team of professionals who support Joe shared enthusiasm and a sense of satisfaction throughout the study.

When Joe’s friends were interviewed, they too, expressed a sense of satisfaction. The satisfaction was not about Joe’s program. It was the satisfaction that they each experienced as a result of being a part of Joe’s life. Bryan and George attended Scouts with Joe and claimed that “these requirements that we have to do, well, Joe does them all
too without having special requirements.” George went on to say, “I don’t really think we should change anything. I think Joe is great!”

The theme of relationships was discussed, observed, and confirmed through analysis of the data. Joe’s social abilities draw people to him. He has formed lasting relationships with the children in his community. His active participation in Scouts, recreational activities, religious-education classes, and every extracurricular activity that is available to his peers has provided him with the most important landscape for learning. His social relationships are reciprocal and his effect on others is lasting.
CHAPTER 5

CARL

Who Is Carl?

Carl was born on March 13, 1988. He is the third of Betty and Bill’s three children. Carl has two older sisters. Betty’s pregnancy with Carl was uneventful and there were no concerns prior to Carl’s birth. Carl arrived 3 weeks early, like his two older sisters. He was very small, swollen, and jaundiced. His parents were advised that there were some concerns and that he should be moved to the neonatal unit.

While he was in the neonatal unit, a nurse was looking at him under the lights and noticed some characteristics of Down syndrome. She mentioned this to Carl’s mom, who was unfamiliar with that term prior to that day. With their permission, a geneticist was summoned to examine Carl. Both of Carl’s parents were present during the exam. The doctor said “Gee, I can’t say for sure because the characteristics are so slight; I am not sure whether or not it is Down syndrome.” A second doctor then examined Carl and had the same conclusion, “Not sure.”

They recommended a genetics test that would take 5 days for the results. In the meantime, both parents started blaming themselves for what they perceived went wrong. They had no experience with Down syndrome, and were very frightened about what it all meant. While they were still in the hospital, a man who worked on the floor and knew
that there was a question regarding whether or not Carl had Down syndrome, made his way to Betty's room. He told her that he knew about Down syndrome and that it was not good. He felt it was appropriate to tell Betty that the baby would never be able to do what others his age could do, and he would probably never be able to do anything more than what a third-grade student was capable of. He went on to suggest that she place him in an institution and "forget about him." Betty and Bill were more than devastated. They had no other information to draw from, and imagined only the worst-case scenario.

The next day, the pediatrician arrived to find a very distraught couple and a thriving baby. He was outraged when he learned of their visitor and took appropriate steps to find out who he was. The doctor worked closely with Betty and Bill, leading them to people who would give them a much brighter view of what Carl's life could be like. It was that day that they learned that, indeed, Carl had Down syndrome and that there was an organization called "The Down Syndrome Congress."

Carl received early intervention through "Birth to Three" services. He received services in his home as an infant. He and his mother participated in small group instruction where a transdisciplinary service delivery model was used to provide integrated services to toddlers with special needs. Betty enjoyed meeting other mothers and became active with the Connecticut Down Syndrome Congress. It was through this group that she learned about her rights and about the many resources and supports that were available to support her and her family.

When Carl was 3, he was enrolled in the local preschool program in the public school. The program was designed to address the needs of students who were at risk or identified as having a special-education label. There were typical peers in the class,
where the model of "reverse mainstreaming" was promoted. Instead of integrating children with special needs into a typical preschool setting, children without special-education needs were invited into the special-education environment. The ratios were healthy and Carl developed some positive social abilities during this time.

The school system was a regional system whereby small towns joined together to form one board of education. All of the towns involved in this regional district were initially rural farming communities. Carl's father had lived in the community all of his life. He was well known. He and his wife received a tremendous amount of support for Carl from their neighbors and friends.

During Carl's preschool years, his mother was told by a school administrator that she was responsible for transporting her son to and from school. When Carl was receiving "Birth to Three" services, his mother remembered learning that transportation was a service that the school system should be responsible for. She requested a Planning and Placement Team meeting and found a copy of her procedural safeguards that indicated rights to receive transportation services for their son. At the meeting, she and Bill informed the team that they knew their rights and expected the school system to abide by the federal laws. Transportation was immediately arranged and Carl had a very positive experience attending preschool. Some of the children he met went on to kindergarten with him.

Carl attended the same school for kindergarten, first, and second grade. When he was in second grade, his teacher approached Betty and Bill, informing them that the second-grade class would be participating in a performance. The teacher wanted Carl to participate, but knew that he was somewhat shy and was not comfortable with large
crowds. Betty and Bill decided that this would be a nice opportunity for Carl, if he was comfortable participating. A role for Carl was identified. He would be the sign carrier and would have to stand in one place without saying anything. The performance went off without a hitch and Carl’s interest in the stage was born.

He moved to a new school for third grade with the same children he had known since preschool and kindergarten. During these 2 years, his parents and school team decided that he should begin to develop more responsibility. For the next 2 years, Carl was responsible for raising and lowering the flag in front of the school with the assistance of the custodian. He never forgot his job and had perfect attendance for the all of third grade. While he was in fourth grade, he was involved in a recycling program. The story was shared by his mother during the focus group interview. The superintendent visited the school 1 day. Carl invited him to help, and his picture was in the newspaper with the superintendent!

The same group of students moved to their third school for fifth and sixth grades. Carl had always had a love for music and stage productions. During fifth grade, he joined the chorus, and at the same time, his parents signed him up for piano lessons. He loved to practice and would sneak down to the music room at school to play the piano every chance he had. When students gathered in the music room for chorus, Carl would always be sitting at the piano when the teacher entered the room.

It was also during fifth grade that Carl’s parents carefully crafted a plan for him to become more independent. “Carl learns best through routines,” said his dad. “We established a routine for him and set it up so that my daughter would hide and watch, and Carl would think he was home alone. This was to make sure he would be safe at all times.
and could be trusted.” Carl passed the test with flying colors. He became a very
independent and responsible young man who would arrive home from school, get himself
a snack, do his homework and other chores, and stay close to the house until one of his
parents arrived home from work.

“Carl has never been treated like an exceptional child in our house.” He has been
raised with the same expectations and responsibilities as we had for our other children.”
Thus, Carl had a number of chores that he was responsible for at home. He was expected
to keep his room clean, including making his bed, dusting, putting laundry away and
vacuuming. He was also expected to set the table before dinner, clear the table after a
family meal, and wash the dishes with another member of the family. He demonstrated
the capabilities to do the entire job independently, when the occasions presented
themselves. Carl fed his two cats every day before he went to school. He was
independent in every aspect of preparing himself for school each day with the slight
exception of acting like a typical middle-school student and resisting the wakeup call in
the morning.

For fun, Carl enjoys classical music, movies, videos, and his friends. He always
had friends. One of the boys who participated in the friends interview lived close by and
had played with him since preschool. His friend’s mother was an aide to Carl 1 year,
which made their relationship closer. It was this friend who informed his mother that
“Carl doesn’t like to look at baby books or stuff for little kids. He’s more like us and
doesn’t like baby things.”

As a sixth-grade student, Carl participated in every aspect of the school
community. Between his chores at home, his participation in his local church, piano
lessons, and occasional opportunities to help a neighbor with a horse, Carl’s days and weeks were quite full.

Carl has a particular love for animals and, according to his parents, animals are drawn to his gentle nature. His many interests paired with his well-developed manners and social abilities made him a popular student and neighbor.

**Carl’s Team**

Based on the IEP for sixth grade, the following personnel are listed as members of his team: A special-education teacher, a special-education teaching assistant, a language arts teacher, a music teacher, a physical education teacher, a science teacher, a social worker, a school psychologist, a speech-language therapist, and the principal. When the team interview was scheduled to occur, I made arrangements initially with the principal, who then identified the special-education teacher as the contact person for the observation, interview, and documents requested. The special-education teacher is considered the “case manager,” the person who coordinates implementation of the IEP and communicates with other team members. Carl’s parents were active members of his team and communicated with his special-education teacher as needed.

Subsequent to the parent focus group, I contacted Carl’s special-education teacher to arrange for the observations and interviews. Together, we decided to schedule the observation and interviews on the day that the team met. Like most middle schools in the state, the students are assigned to teams, and teachers work on teams to plan instruction.
and address the learning needs of the students. An observation of Carl occurred that day until it was time to meet with his team.

The team met in the classroom of one team member. The special-education teacher, the technician who videotaped, and I entered the room at the same time. The three teachers in the room represented social studies, math, and science. After introducing myself to the math teacher, she quickly announced, “I don’t work with Carl.” I then introduced myself to the social-studies teacher and the science teacher. I asked if there were any other team members planning to attend the meeting and was told that “this is who usually attends our meetings.” Then the social-studies teacher said, “I don’t really work with Carl. He is in my class, but I don’t expect him to do what the rest of the class is expected to do, so I don’t know what I can contribute to your questions.”

With that, I explained to the team what I was hoping to accomplish by interviewing members of Carl’s team. I learned that Carl had a great deal of success in the unified arts classes and that there was no mechanism for that group of people to meet to plan or share their experiences. As time went on, it became more apparent to me that this was not the group of people who would be able to provide information about Carl’s experiences as a sixth-grade student. I indicated to the technician that filming should end and encouraged the team to proceed with their usual agenda. We exited the room. The special-education teacher offered to discuss my research needs with the principal and arrange for another opportunity to meet with people who knew Carl.

I then scheduled an additional day of observation for Carl and communicated with the principal personally about the possibility of arranging another meeting with people who knew Carl. The second meeting was scheduled.
The personnel who participated in the team interview included the special-education teacher, the teaching assistant, the language-arts teacher, who was not in school on the day of the first interview attempt, the PE teacher, music teacher, and science teacher. The large paper was posted on the walls with the interview questions. The team members who responded to the questions knew Carl and had many positive and successful stories to share.

The special-education teacher was a young woman who had been teaching for just a few years. Her enthusiasm, responsiveness to Carl, and knowledge about his educational program were quite helpful. She was proud of his accomplishments and had been his teacher for the past 2 years. She was primarily responsible for the implementation and data collection relevant to his IEP. Her young and energetic style was contrary to the first group of professionals who were identified as Carl's team. She was apologetic for the challenges encountered during the first attempted interview. When asked to share a positive story, she told the group about Carl's attempts to hide from personnel in an attempt to be more independent. "He didn't want to be helped."

The special-education aide was a woman who had worked in the school system for 5 years. Prior to her work as an aide, she was employed in a variety of part-time jobs while she raised her children. She had no formal special-education training and worked with Carl in three of his classes each day. In this school, the students receive paraprofessional support from a variety of aides. He did not have one person assigned to him like the other two boys in this study. I observed this aide working with Carl in the special-education resource room. She sat at the table with Carl for the entire time he was working, taking an occasional break to chat with him about something unrelated to his
work (at his initiation). When asked if she enjoyed her job, she responded, “I like the variety and the kids.”

The language-arts teacher was the first person to share a positive story about Carl. She also said, “I see social interaction to Carl and from Carl. It feeds on itself in a circular way. It benefits both Carl and the other students.” She also contributed to the question regarding the successful elements of Carl’s program by saying, “The consistency that he has had in this district... he has been with the same kids for 7 years. They know him and accept him as part of their world and vice versa.”

The PE teacher was a man who was very knowledgeable about Carl’s ability to participate in his physical-education class. He shared with me his hesitation to give Carl too much attention versus not enough help. He went on to say that “when you see the other kids helping him, it’s even better.” He had known Carl for 2 years. He had been a teacher 7 years and had no prior experience with students with disabilities until becoming employed in this school district where Carl was one of the first students with mental retardation to be enrolled in regular-education classes.

The music teacher had known Carl for 6 years. He had been an educator in the school system for many years. He was the most talkative member of the interview team and had the most experiences with Carl. In sharing a positive story, he started by saying that he had known Carl since first grade and that “this school has been magic for him, just magic.” He also pointed out the “wonderful friendship” that existed between Carl and one other boy in his class. He pointed out the fact that they had a reciprocal relationship. This teacher also said that “years ago, when I first started teaching, those kids were segregated. They were segregated in a self-contained classroom all day long. We never
saw them. So, what makes this so successful? Mainstreaming! He’s part of us all the
time.”

The science teacher was present at the first attempted interview and the second.
She had been teaching for several years and had been in the same school system for all of
them. She also lived in the community near Carl. When team members were sharing
their stories, she said that she did not really have a story, but commented on the fact that
“Carl is so warm and courteous. He feels very comfortable coming to me and telling me
something about what he observed in Science.” She also identified her time available to
Carl to be a barrier. “I have 20 other students in the class and have to keep them on task,
so rarely do I have the time to work one to one with Carl.”

The people who were identified on the IEP were not necessarily the team of
people who collaborated to plan for Carl’s educational services. Based on the
experiences I encountered, it was somewhat difficult to identify who was on the team and
what role each one played. It became clear that there were people on Carl’s school team
who knew him well and valued him as a student in the general-education classes. At the
same time, there were teachers who did not know him and merely allowed him access to
their classrooms. The observation in the Social Studies class confirmed this finding. The
work that Carl was doing in the class was not designed by the teacher. It was designed by
the special educator, based on knowledge she acquired at the team meetings that occur
with the academic teachers. The only interaction that occurred between the teacher and
Carl was a quick acknowledgement that occurred as he passed by Carl, saying “Good,
Carl.” Carl did not respond. He kept working.
Carl's team was fragmented. The special-education teacher was the conduit of information. However, the information and collaboration did not appear to flow in both directions. The people who work most closely with Carl in delivering services to him did not meet on a regular basis. They lacked opportunities to share relevant information about Carl. There was little evidence of infusion of knowledge, and no evidence of a common focus. The possibility of collaboration or opportunities to address embedded skills was not a consideration. This team was in sharp contrast to a collaborative team that knew the student and planned his accommodations. In spite of their limitations, Carl’s special-education teacher and the participants in the second meeting were able to answer the interview questions, but they had met only for that purpose and would likely not meet again to plan or assess his progress.

**Carl’s Educational Program**

**The Individualized Educational Plan**

Carl’s IEP reflected a planning meeting that occurred in May 2000. The plan was developed for Carl’s sixth-grade year. The team members who participated in the planning process included the principal, Carl’s father, his Language Arts teacher, his special-education teacher, the school psychologist, and a representative from DMR, the state agency that supports adults with mental retardation. The following recommendations were listed on the IEP:

1. Reading instruction will occur daily
2. Math instruction will occur daily
3. Writing support will occur daily

4. Speech/language service will occur twice a week.

5. Social/Language group will occur once a week

6. One-to-one para-professional in all academic areas

7. Extended school-year services will occur

8. Narrative report card

9. Resource support will occur once a week


Carl’s team discussed his plan for sixth grade. The minutes attached to the IEP indicate that there was agreement with the plan.

Carl’s present levels of performance were described by his team. His learning strengths included the following: He is a happy, friendly child, cooperative, has good social skills, good behavior, sight word recognition, and he is described as independent. His learning needs include reading, specifically decoding and comprehension, math skills, written expression comprehension, and language.

Carl’s IEP included seven goals. The first goal addressed improvement in math skills. The objectives described instruction in counting, writing numbers, adding, sequencing, use of a clock, and a calendar. The second goal addressed writing skills. The objectives addressed instruction in spelling, sentence completion, and writing a letter to a friend. The third goal addressed reading skills. The objectives addressed instruction in sight words, reading for pleasure, identifying characters, settings, and events in a story, and comprehension. The fourth goal addressed increased independence. The objectives
described instruction in the use of a schedule, organization of personal belongings, and increased skills in working independently.

The fifth and sixth goals addressed Carl's communication skills. The objectives described instruction in following directions, answering questions, improved vocabulary, articulation, semantics, syntax, and pragmatics. The last goal on the IEP addressed social language skills. The objectives delineated instruction in eye contact, initiation, and reciprocity.

The IEP addressed the hours of service. Carl was scheduled to receive 11 hours and 12 minutes of special-education services per week. Two hours and 5 minutes were identified for related services, and he was scheduled to receive 16 hours and 42 minutes of regular-education instruction, with a total week of 30 hours.

The last page of the IEP defines the modifications and adaptations in the regular-education settings. The materials identified included computer access and consumable workbooks. Tests and quizzes were scheduled to be modified using a variety of strategies. There were no indications for environmental or behavioral support needs. Instructional strategies were identified. They included the use of manipulatives, oral and visual cues, drill and practice, and computer-assisted instruction.

Consideration of Best Practices

Williams et al. (1990) identified nine best practices that were used in analyzing Carl’s educational services.
1. Age appropriate placement: Carl attends the school he would attend if he did not have a disability. He was in sixth grade, which was age appropriate.

2. Integrated delivery of services: Carl did not have the benefit of a fully integrated delivery of services. The special-education instruction was isolated for a portion of his day. He received speech and language services in small group and separate settings. The communication mechanism that is necessary for the delivery of integrated services was lacking.

3. Social integration: Carl is well integrated with his peers when he is in the regular-education classes. The friendships he has and the support of his peers far exceeded my expectations. Carl moved about the building independently, to the point where he emphatically distanced himself from the para-professional in the hallways. When classes changed, Carl would walk with friends while greeted by others going in the opposite direction. His friends Ben and Sam were in many of the same classes as he. During computer class, Ben helped Carl with his work, which was an effective strategy for both students. Carl was able to work with Ben when the science class went outside for an observation of the clouds. Carl was much more interactive with Ben than he was with the para-professional.

The social relationships that occurred in Carl’s life on a daily basis were impressive. Carl had friendships that were genuine and reciprocal. He was observed to be somewhat shy with adults, but quite comfortable with his friends.

4. Transition planning: Carl’s school district has the students moving to new schools every 2 years. There was evidence of transition planning for each move. He was
scheduled to move to a new school for seventh grade. The planning for that move was in progress during this study.

5. Community-based training: Carl does not receive any training in the community. He spends all of his day at school with his peers. Based on reports from the school team and his parents, he has demonstrated the ability to generalize skills from one environment to the next, and did not appear to need such services at this time. When he is in high school, community-based services will be reconsidered, according to his teacher and parents.

6. Curricular expectations: There was no evidence of systematic planning or longitudinal monitoring relevant to curricular expectations. Carl’s team was lacking in planning and collaboration skills. The expectations and monitoring of Carl’s program rested solely on the shoulders of the special-education teacher. This was evident in the documents, observations, as well as the first attempted team interview. The academic teachers relied on the special-education teacher to gain information and plan accordingly. Carl was observed on two separate occasions. One day was a shortened school day. The second observation occurred on a day that included classes that were considered Carl’s preferred classes. Carl spent the majority of his day in regular classes with typical peers. In the Science class, Carl was expected to complete the same lab assignments as his classmates. The para-professional worked with him individually. Carl would have enjoyed working with his classmates, based on his frequent attempts to see what they were doing.

In Art class, Carl worked on a project and received support from Ben. Together they cleaned up their work area, and left the room together to head for their next class.
Carl's favorite class was music. The teacher had a special interest in Carl and allowed him to play the piano when he got to the room. Sometimes, he and Ben would play a duet until the teacher arrived.

The work samples submitted for this study included work from math, computer class, and social studies. All of the work was designed by the special-education teacher. Some of the instructional materials were from the Internet, some were from a workbook, and some were teacher-generated. The work addressed Carl's ability level, but was somewhat isolating to him. For example, the work he did in the Social Studies class was completed while the teacher was lecturing to the rest of the class. The teacher did not design the instruction or collaborate with the special-education teacher. He did not evaluate the work either. His grade was based on the recommendation of the special educator.

Carl spent two class periods totaling 80 minutes in the resource room during one of the observations. During this time, he worked on a reading assignment and math. There were a few students in the room for the first period, but Carl did not interact with them. He sat at a separate table with the para-professional. During the second period, he was the only student in the room. It was unclear to me why the instruction was provided in an isolated setting.

7. Systematic data-based instruction: Carl's team did not have a planning time that was designed to address his learning activities. The data that were used for evaluation included work samples and anecdotal information from the special-education teacher. There was no data collection system in place beyond the work samples and formal assessments.
8. Home-school partnership: Carl’s parents had a presence on the team and had daily communication with the special-education teacher via a notebook. During the interview, it was clear that the members of Carl’s team and his parents had a positive working relationship.

9. Systematic program evaluation: The IEP was evaluated quarterly. The team did not have any meetings scheduled to assess progress to date or determine whether or not changes in the IEP were necessary.

Summary

Without a doubt, Carl’s friendships are the pillars of success in his educational program. The relationship he had with Ben was observed and discussed by his team. Throughout Carl’s day, he interacts with many people. However, the friendship that exists between these two boys was noteworthy. When the students who were selected to participate in the interview responded to the questions, they conveyed a clear message. “Carl is more like us than he is different.” Carl had attended the same schools as his non-disabled peers since preschool. This small rural community provided a landscape for the most meaningful relationships to grow, not only for Carl, but for Ben, Sam, and others.

The feature that made Carl’s program unique is his community. Carl lives in a small community where “everyone knew each other.” Carl’s father grew up in this community and had attended the same schools where Carl’s older sisters enjoyed successful experiences before attending college. Many of the teachers in the school had taught there for many years, knew the family, and knew Carl before they had him in their
classes. The students attend schools for 2 years at a time, then they move on to the next school. Carl has always been in regular education classes. All of the students in his grade knew him, supported him, and included him in their social circles.

A Day in the Life of Carl

The following is a story that was written using the data collected relevant to Carl’s educational experience. It is a composition created for the reader to understand some of the highlights that occurred in Carl’s life during this study.

There was no alarm necessary. Carl was up and dressed by 6:30 a.m. It was his last day of sixth grade with a very busy day ahead of him. Before he started down the stairs to make breakfast, he made his bed, organized his Matchbox™ truck collection, put the folded laundry in his drawers, and knocked on the door to his parents’ room saying, “Wake up.”

Carl set the table for himself, selected a box of cereal, poured a full bowl, sliced a banana, retrieved the milk from the refrigerator, and poured a tall glass of orange juice before sitting down. While eating his cereal, he turned on the radio, adjusted it to the public radio station to hear the morning news amidst a variety of classical pieces. His father entered the kitchen from the outside door. He had been out back getting the lawn mower ready for Carl to use later that afternoon. “You’ll wait until I arrive home before you tackle the yard, Carl. You know I have some new trees planted out there and I want to be sure that you see them and not run over them!” Carl laughed. “I’m a good driver,” he said.
Carl’s mother entered the kitchen ready for work. She reminded Carl of the list of errands that he would do with his sister once she arrived home. “Judy will drive you to pick up your suit, and there’s money on the counter for you to get a pizza on the way home.” “OK, Mom,” said Carl.

The bus picked Carl up in front of his house. The next stop was for his friend Sam, who has been taking the same buses with Carl since the first day of kindergarten. “Can you believe this is the last time we have to take this bus to this school? I am going to be so happy tonight when everything is finished and we can just do nothing for the summer.” Carl responded, “My sisters are coming.” Sam said, “My whole family is coming. I’ll probably fall across the stage!” Carl laughed and the bus continued on to gather more students until all the seats were full.

Once at school Carl cleaned out his locker and sorted out what he needed for his first class, which was Science. He pulled his book out of the backpack and made his way down the hall. Carl sat at a table with Ben and Sam. The students were instructed to pass their books to the front of the class and clean the equipment on the tables in preparation for summer storage. Once the books were in the front of the class, Carl noticed the boxes that were already full. Next to the full boxes were two empty boxes. He picked up both boxes, handed one to Ben, and gestured for the two boys to help put the books in the boxes. Ben and Sam both had huge smiles on their faces as they mustered the energy to help.

The Science teacher quickly acknowledged Carl’s efforts and pointed out that he is always the first to offer assistance. Science class continued with all efforts put towards cleaning and organizing.
All of the students from the Science class moved in unison towards the computer lab. The lab was filled with new computers and state-of-the-art editing and printing equipment. On the wall was an award that the teacher received for her role in securing a technology grant for the school. Carl entered the room, headed for the printing and copying equipment, hitting buttons and switches in a systematic manner. There were four students who joined Carl in the back of the classroom. The teacher reminded them that they were continuing to print the programs for the “Stepping Up” ceremony that evening, and that they should work efficiently. Carl pushed a button and in a matter of minutes, he and his classmates were folding the stapled booklets and placing them on a cart that would make its way to the auditorium later that day.

When all of the programs were printed and folded, Ben and Sam approached Carl, asking him if he wanted to play the videogame that Ben had displayed on his computer. The boys engaged in the game, laughing, sighing, and making middle-school sounds until the class ended.

Carl’s next class was Art. The students in the class were putting finishing touches and their signatures on a painting that was made by some of Carl’s artistically talented classmates. Carl wrote his name right next to Ben’s and Sam’s. The painting would be presented to the school that evening.

The sixth-grade students were summoned to the music room to practice for the performance that evening. Carl was the first to arrive in the room and resumed his typical seat at the piano until the Music teacher arrived. One student sang a solo, while another student practiced a song on the flute. Carl applauded and acknowledged his classmates. The whole class sang selected songs and practiced entering and exiting the
stage. Carl actively participated in the rehearsal, including a very special role that was
designed just for him.

At the end of their practice, the students made their way to the cafeteria where
they ate lunch. Carl took out the sandwich he had made the night before, then purchased
a carton of milk with his two quarters. He sat with four other boys. Two of the boys
were from different classes and see Carl, Ben, and Sam only at lunch. The boys ate
quickly and made their way outdoors for 10 minutes of basketball. Carl decided to pass
on basketball and made his way back to the music room where he sat at the piano once
again, plunking out the tune in his head.

Carl’s special-education teacher found him in the music room where she sat with
him for a few minutes. They talked about his summer plans, which included a full
schedule of tutoring and recreational activities. Together, they exited the music room,
walked down the hallway and entered the special-education classroom, where Carl had
received support from her and the Instructional Assistants for the past 2 years. Carl
organized the papers that he was taking home, and then organized his backpack for an
early dismissal.

The buses delivered the students to their homes. Once Carl arrived home, he put
his backpack in his room and immediately finished the chores that were left from that
morning. When his father arrived, Carl reminded him that the lawn mower was as ready
as was he. He got on the mower, started it up, and made his way around the entire yard,
designing a symmetrical pattern and carefully avoiding the new little trees. There was a
broad smile on Carl’s face during the entire job.
When he was finished, he and his sister left for their errands. They stopped at the store and the dry cleaners. Carl went into the cleaners alone while his sister waited in the car. He gave the woman the slip of paper from his wallet and handed her more than enough money. She gave him change and he stuffed it into his pocket as he looked at his suit and thanked her. Their last stop was for pizza. Carl entered the pizza restaurant and placed his order by pointing to the item on the menu. “One large,” he said. The person behind the counter knew Carl. He said, “So Carl, are you ready for the summer?” Carl responded “Yes,” while placing a dollar bill on the counter. “Change, please,” he said. With that, four quarters were given to Carl. He thanked him and made his way over to the soda machine.

He put two quarters into the vending machine and pushed the buttons for a diet soda for him and another for his sister. When his pizza was ready, he and his sister headed for home. He ate two slices, drank a glass of milk, and excused himself. He was the first in his house to be showered and dressed for the “Stepping Up” ceremony that evening. While the rest of his family dressed for the occasion, Carl sat at his keyboard. He practiced the pieces that were assigned by his piano teacher, then he played the songs that he liked and had memorized. Within minutes, the whole family was ready and on their way out the door.

The students and their families arrived and filled the auditorium. Carl and his family found enough seats to accommodate his sisters and their gentleman guests. Carl’s piano teacher was there as well. Her husband was a teacher in the school, and she had a special interest in the performance that evening.
The programs that the students made and the art work that they designed were acknowledged and appreciated by all. Students' names were called and awards were given for a variety of academic achievements. Each department gave an award for excellence. Ben won the technology award. Carl cheered when Ben's name was called. The last award was from the Music Department, presented by the Music teacher. Carl's parents were not prepared to hear his name called. His teacher described him as one of the most dedicated and sincere students who had participated in the music programs. He went on to say that when he was growing up and first teaching, students like Carl were never included in the school community. He went on to describe what an honor it had been to watch this "Pioneer" blaze the trail for so many other students. He then invited Carl to come up to the stage and play a piece for the audience. Carl sat at the piano, opened the music to his song, and played it perfectly. When the music stopped, everyone was on their feet cheering while Carl's parents looked at each other in amazement.

Carl bowed and exited the stage, lining up with his classmates to receive their certificates. Every student surrounding Carl gave him positive feedback all at the same time. The mysterious man who visited Carl's parents on his second day of life and painted a bleak picture for them should have been there.

Themes and Impressions

"Having Carl made us realize that material things in life are not the most important." "He has changed a lot of things in our lives, all for the better." That was the first statement that was made about Carl. His mother went on to say that he was popular and was known in the community.
Carl’s parents educated themselves about Down syndrome within the first weeks of his birth. An extremely unfortunate incident occurred when a mysterious visitor relayed a doom-and-gloom picture to Carl’s parents shortly after they heard that their son may have Down syndrome. Fortunately, their pediatrician assisted them in forming a positive vision of the future when he arrived the next day. Carl’s parents learned about the Down Syndrome Congress. They networked with other parents and learned about the range of support services that were available to them.

Themes of relationships and learning emerged early in Carl’s life when he began receiving services from “Birth to Three” in his home. His mother welcomed the professionals and actively participated in therapy sessions that were designed to stimulate his development. Carl made significant progress in his motor and cognitive skill development. By the time he was 2, he was ambulating independently and using words to communicate his needs. Carl’s two sisters had a significant role in his early development. They reinforced every little step he made in the direction of progress, and at the same time, were not allowed to dote on him or do things for him that he was able to do for himself. That was a tall order for his sisters who saw him as a “living doll.”

Carl’s dad said, “We never treated Carl like he was special.” Because of this, he was expected to behave in an age-appropriate and acceptable manner at all times. He also had chores assigned to him throughout his life, and was expected to be as independent as possible. As a result, I met an extremely responsible and independent sixth-grade student who loved school.
Carl's educational program provided him with many learning opportunities. He smiled the majority of his day. His access to typical peers and participation in regular education activities were observed and confirmed in the team interviews.

Carl's parents said they were very satisfied with his educational program. From their perspective, he had made significant gains and had a network of social relationships that provided their son with rich experiences.

Carl's team shared stories about Carl that illuminated his sensitivity for others, his zest for independence, and his love for music. They understood the influence his peers had on him, but more importantly, the influence he has had on them. They missed, however, the importance of team process and collaborative planning as it related to the implementation of Carl's educational services.

The initial codes for Carl's data showed "independence," "friendships," and "access to typical peers" as the most frequent codes. This led to a solid theme of social relationships and learning that were evident throughout this study.

The most successful aspect of Carl's educational program became most evident when he was observed in classes with his friends. The videotapes that were used in this study provided me with unequivocal evidence that there was nothing more impressive than the beauty of this friendship. The special-education teacher was also a strength in Carl's program, in that she did it all. Because there was a lack of team process, she managed to keep his program meaningful and progressive. She also recognized the significant role that his friends played in supporting him.
This very responsible and poised young man clearly provided his team with opportunities to experience the themes of satisfaction, relationships, and learning on a daily basis.
CHAPTER 6

NED

Who Is Ned?

Ned is the third of three boys in his family. He has one brother in high school, one in college, and he lives with both parents, Lana and Will, in a small rural farming town. His parents are well educated. His father is a graduate of MIT and his mother just finished a degree in law. He has lived at home with his family for all of his life. He was diagnosed with Down syndrome the day he was born. He presented with some medical issues, but after oxygen and emergency intervention, he was a thriving, healthy baby. Both parents describe the news of Ned’s diagnosis as initially traumatic. It caught them completely off guard. Will shared an epiphany he had when Ned was just a few days old. He held him in his arms and looked into his eyes thinking, “What will your life be like? How will we do this?” He then thought, “Nobody knows what their life will be like. Nobody knows what lies ahead. He’s not any different from any other person who is new to the world. We will give him every opportunity that we will give his brothers. It will be OK.”

Ned received early-intervention services in the form of home support when he was an infant. He participated with his mother in small-group interdisciplinary-team services and a parent support and training group. When Ned was 2 years old, his parents
joined a group of parents from the local Arc that advocated for the full inclusion of children with disabilities in their neighborhood schools. With a group of other parents, they became educated about their son’s disability, learned about the range of services and resources that might be available to them, and became friends with other parents of children who have Down syndrome. This group of parents and their new found knowledge strongly influenced local and state policies and the chain of events that followed in Ned’s life.

When Ned was 2 and a half, his parents informed the school system that he would be expected to attend regular-education classes in his neighborhood school. The district administrator was less than receptive. He indicated to them that there were programs in place that the district was prepared to provide. He also indicated to them that the integrated preschool-program that was selected by the parents would not be their recommendation. The relationship between Ned’s parents and school personnel had a very negative start. Nonetheless, Ned’s parents were very clear about what they wanted. They hired an attorney who filed for due process. The district and the parents reached a settlement agreement, allowing Ned to attend the school selected by the parents, with the intent that he would remain in an integrated preschool until placement in kindergarten in his neighborhood school.

Developmentally, Ned showed delays in all motor and cognitive areas. He developed good eating skills, was walking by the time he was 15 months old, and was using words to communicate by the time he was 3. He was a very social little boy with a sophisticated sense of humor. He imitated his brothers, who took great pride in teaching him a variety of motor and language skills that would make him very popular among
their peers. The whole family was involved in hockey. Ned would accompany his mother early in the mornings transporting his brothers to practices and then spend weekends traveling to games throughout New England. By the time Ned was 5, he was up on skates and participated in practices with other little boys!

Ned attended kindergarten in his neighborhood school with the assistance of a para-professional. During this year, again his parents engaged in a struggle with the district over the delivery of related services. His parents insisted that Speech, Occupational Therapy, and Physical Therapy be provided to Ned in the classroom. They had independent evaluators assess each of the skill areas in question. All of the evaluators recommended integrating the related services into the kindergarten classroom. Again, the district settled its disagreement with the parents and services were hesitantly provided in the regular classroom.

During Ned's early years in school, he presented his school team with some behavioral challenges that led the school district to develop a behavioral support plan. Ned resisted engaging in some activities. He refused to follow directions, then would become totally limp and fall to the ground. Although he was quite young, he was not a small child and was quite difficult for the school personnel to manage at times. The district personnel thought that he was not happy in the regular classes and that he might do better in a separate setting. The district suggested the possibility to the parents but did not make any progress with their proposal. Instead, the parents asked for another evaluation and a consultant who could work with the district. Improved instruction in social skills and communication addressed the challenges; however, Ned continued to
have a reputation for being “stubborn.” He responded well to natural consequences as time progressed.

When Ned entered first grade, the para-professional who was assigned to support him had no training, but had the right personality to work effectively with him, the school personnel, and his parents. She learned how to facilitate Ned’s participation in classroom activities, and developed the skills needed to adapt the curriculum and modify instruction to meet Ned’s learning needs. A review of Ned’s IEPs shows that he had goals and learning objectives in academic and cognitive areas, self-help, communication, gross and fine motor, and social development throughout all of his elementary years.

He received direct instruction in reading and math in the regular classroom. The special-education teacher worked directly with Ned in the classroom while other students worked on the same subject areas. He participated in small group instruction as well, and developed some very useful academic skills. All of the other areas of instruction were supported by his para-professional, who continued to support Ned throughout his years in elementary and middle school. As the years progressed, his facilitator spent less time working directly with him and more time designing instruction and adapting the curriculum under the guidance of a special-education teacher.

Ned was invited to birthday parties. He played in the neighborhood with other children his age and younger, and continued to accompany his family on weekend trips to hockey games. He participated in Cub Scouts with the support of his dad. He participated in every field trip and extracurricular activity that involved the school community. He sang with the school chorus and is currently involved in a bowling league.
Ned’s learning strengths are found in his ability to decode words, read sight vocabulary, and answer questions relevant to social studies and history. He learned how to use a computer, and effectively participates in cooperative learning activities with his classmates. He can use a calculator to complete a variety of math problems; however, math is his least favorite subject. Completing homework assignments is also far down on Ned’s list of preferences. He is willing to complete homework assignments at school, but is quite resistant to taking the work home and returning it completed.

Ned has a sophisticated sense of humor. He likes to imitate people and mime situations. During the observation, I found Ned gesturing at various times, indicating to me that he is always thinking and looking for an opportunity to laugh. For example, when he was in chorus, his favorite school subject, he was singing a song with the class that sounded like a hymn. During this time, he gestured the “sign of the cross” and bowed a few times as if he were the priest. On another occasion, when his French class was planning their trip to the theatre, he started to hum and conduct the music he was familiar with when the teacher mentioned the name of the show. I do not believe others saw what I saw, but was later told that he has many similar antics that people find very entertaining. His classmates all say that he is funny and popular.

When Ned is not in school, he enjoys video and computer games, movies, sports, and girls. His older brother is currently a history major in college. Ned shares his brother’s interest and has become a Civil War buff. He has participated in reenactments, shows, and enjoys museums.

Ned’s greatest challenge is in communication. He has a difficult time articulating clearly enough for people to understand him. People who know him well, however, learn
how he communicates and eventually understand him. He has been with his same-age peers since preschool. They do not have any difficulty understanding him. In class, there were occasions when the teacher would turn to the students and ask them to interpret for Ned. They always seemed to know what he was saying.

Ned enjoys school and has made significant gains in academic skills. He is a very social young man who never misses an opportunity to interact with his peers. He moves about the school independently and follows the same schedule as his typical peers. The para-professional who has been with him throughout all of his years is a very skilled facilitator who initially took on a passive role with the teams each year. As she came to know his abilities and the complexities of skills needed for successful integration, she became a strong advocate for him. She is held in high esteem by all of the members of Ned’s team, and is trusted and respected by Ned’s parents.

Although Ned’s parents have had differences with the school personnel due to their unwavering commitment to his placement in regular education classes, the teams learned to work collaboratively on behalf of Ned and continued to enjoy the many successes he had throughout the years.

Ned entered eighth grade after a very successful experience in seventh grade.

Ned’s Team

During Ned’s seventh-grade year, his team included several people. In addition to both of his parents, who attend every meeting together, the following personnel make up his team: The principal, a special-education/language arts teacher, a speech language
therapist, an occupational therapist, a physical therapist, a communications teacher, a math teacher, a para-professional, and a French teacher. All of these people participated in the team interview, with the exception of the PT and OT. They were not in the building that day.

Ned's team met every Tuesday. The meeting was scheduled for .5 hours per week on his IEP. The meetings were informal in that people stopped in with instructional information, new curriculum ideas and units, or shared information about Ned. Who attended the meeting was dependent on what the agenda was. Margaret, the para-professional, operated as the facilitator in that she was the conduit of information, and had direct contact with all of Ned's teachers. She relayed information to the various team members and was the person who managed the data that were collected relevant to his IEP goals and objectives.

When I initially communicated with the principal, she welcomed my involvement and assured me that the time I requested from the team would not be a problem, and that I could meet with the team during their regularly scheduled time, with additional time planned to accommodate my request. Ned's team was the first team that I interviewed subsequent to the parent focus group.

I had direct experience with seven team members from Ned's school. Throughout this study, the para-professional's ability to facilitate Ned's educational program had been hailed as the most successful aspect of his educational services. She is a woman who has children in college or are young professionals. She had not been employed for several years before applying for the job to be a special-education aide in the public
schools where her children were "successfully educated and subsequently did well in college."

Margaret had no formal special-education training. All of her training had been "on the job," with the exception of a few training workshops that she was able to attend. She started supporting Ned when he entered kindergarten. She found Ned to be fun and a challenge at the same time. She was the first person to respond to the first question posed during the interview (What is your favorite story?). When she told the story about Ned's friends walking him around the entire track when he was ready to give up, she cried. She said, "I still cry when I think of that." During her 7 years with Ned, she has learned a lot about teaching, learning, designing, adapting, communicating, and facilitating. She was a delightful person to interact with and has the highest regard for Ned's parents, his abilities, and his future. As Ned's parents said, "She is a real advocate for him."

The special-education teacher was also his language-arts teacher. She provided reading instruction to him using the Wilson Reading Program. This teacher had been teaching for several years and is a sister to a woman who has Down syndrome. She also shared with me that she is married to a man who also was a sibling to a person with Down syndrome. "We met at a Christmas party where our siblings were attending the party. We were standing on the sideline and started talking." Her interest in special education became obvious. She was enthusiastic about the progress that Ned had made during the year with his reading skills. She was also impressed with his ability to "act like he wasn't paying attention, and then came back with the right answer." Ned also participated in language arts class with this teacher. "He actively engages with the other students, and is responsible for the same things the others are."
The speech/language therapist had been working in the school district for many years. She provided consultation to the team regarding communication strategies, but was not listed on the IEP as a service. Ned's parents insisted that the services of this professional be provided in the regular education settings. The Speech Therapist disagreed with them. She felt that Ned needed direct service in a separate setting to address his problems with articulation. The Planning and Placement Team decided that she could be available for consultation, but the parents decided that they would be comfortable with no service at all. She participated in the team interview. She expressed her concern about Ned's ability to "function independently as an adult" without participating in a "life skills" class.

The three regular-education teachers who participated in the team interview and had included Ned in their regular education classes had several things in common. They all had an active role in planning his participation in the classes. They were the educators ultimately responsible for instructing Ned in their classes, with the assistance of Margaret, and they graded Ned based on individualized criteria and collaboration with the other members of his team.

"Mine is not really a story," said the French Teacher during the interview, but I would just like to say that this is my first experience of having a child with Down syndrome or even having a child with that level of disability . . . so I was really moved by how nice the kids are and how well they do with him, how helpful they are with him. It has been a very positive experience for me, and Ned is a very likeable kid himself." During French class, the teacher takes a few minutes out of each class to have direct interactions with Ned and monitor his progress.
The communications teacher had been working with Ned and Margaret on developing Ned's project for his class. All students were responsible for a full class presentation on any research topic of their choice. On the day of the direct observation, this teacher offered to videotape Ned's presentation on "Hockey" and send it to me to document the results of his efforts and provide me with additional data. The presentation was videotaped and sent to me. I viewed the tape and included it in this study. The communications teacher expressed his enjoyment in having Ned in his class. "He's really funny."

The math teacher participated in the interview, but was not particularly active. She said, "I do not understand why Ned is in a class that does not address his learning abilities in math." She did not have a positive story about Ned, and was the least active member during the interview.

The principal played an active role in the team interview and had a presence in the classrooms during the observations conducted. She interacted with all of the students extensively. This principal knew Ned personally, and contributed significantly to the interview process. She was proud of the program that Ned had and was complimentary to her staff during the interview, saying, "I think the level of sharing among adults is a key to why this program is successful."

Ned's team could be described as "collaborative." They demonstrated participation, decision making, infusion of knowledge from different disciplines, problem solving, and attention to embedded skills throughout the educational program. Additionally, this group of people appeared to have a common goal of including Ned in every aspect of the middle-school community. In spite of their variety of attitudes and
opinions, Ned has the benefit of receiving educational services in an integrated and collaborative fashion. Ned is included because of his team.

**Ned’s Educational Program**

The Individualized Educational Plan

Ned’s IEP reflected a planning meeting that occurred June 2000. The plan was developed with the intent of implementation during seventh grade. Participation in the planning process included the school principal, Ned’s parents, the special-education teacher, the speech language therapist, a guidance counselor, the occupational therapist, a math teacher, Ned’s para-professional, and the special-education administrator from the district. Together, they planned an IEP that addressed Ned’s learning goals and objectives for seventh grade.

The PPT made several recommendations that included the following:

1. Continuation of aide support
2. Reading instruction using a phonemic-based program
3. Math, French, and Communications classes in regular education classes
4. Use of Assistive Technology (laptop computer)
5. An OT evaluation
6. A PT evaluation
7. Discontinuation of Speech Language services (per therapist)
8. An Independent Speech Language evaluation per parent request
9. A PPT meeting was scheduled for November 2000.
10. Triennial evaluation to include curriculum-based assessment, technology evaluation, and speech.

The PPT minutes described the discussions that occurred during the planning meeting, culminating in the recommendations delineated above.

Ned's present levels of performance and concerns were described by the team. His strengths included special and visual concepts, calculator skills, class participation, peer relationships, great sense of humor, comprehension of grade level concepts, persistence in communication, reading aloud, retention of concepts taught, and comprehension of materials. His learning concerns or needs included independent work habits, stubbornness, works slowly, abstract concepts, and homework completion.

The learning goals and objectives were delineated in this document. The first two goals addressed Ned's reading skills. Using a phonemic-based curriculum, the learning objectives identified the skills that Ned would learn as a result of participation in this class. The third goal addressed writing skills. Using a computer and software identified in the objectives, Ned would learn to use a graphics organizer. His IEP also addressed improved skills by writing paragraphs and using correct punctuation. The fourth goal addressed math skills. The objectives identified improved skills in computation, fractions, decimals, percentages, and word problems.

The IEP addressed the hours of service. Ned was scheduled to receive 11.75 hours per week of special-education instruction. This was directly related to the reading instruction he would receive. There was 1 hour per week identified for related services, limited to the first month of school whereby the PT and OT would consult with the team regarding any physical accommodations necessary for Ned. He was scheduled to receive
20.25 hours of instruction in regular education settings, with a total week of 33 hours. The most significant item on this page was the identification of team planning time at .50 hours per week. That is, the team had regularly scheduled planning meetings.

The last page of the IEP addressed modifications and adaptations in regular education. The boxes checked indicated that Ned would use a variety of equipment, including a computer, calculator, supplementary visuals, modified work, and a tape recorder. Tests and quizzes would be modified, grading was based on effort and work, and he would use an assignment book. Behavior support included the use of cues and a positive reinforcement plan. Instructional strategies were delineated, including a multisensory approach, concrete examples, computer-assisted instruction, and a vocabulary word bank.

Consideration of Best Practices

The nine best practices, identified by Williams et al. (1990), were used as a guide in analyzing Ned's educational services.

1. Age-appropriate placement: Ned is in the school he would have attended if he did not have a disability. He is the same age as his classmates and has attended his neighborhood school since kindergarten.

2. Integrated delivery of services: Ned's services were integrated; however, there remained a difference of opinion regarding speech and language services. During this study, Ned did not receive direct services from a therapist. The team meetings provided an avenue for collaboration and planning to occur in an effective manner. During the observations and interviews, there was evidence that the team collaborated in developing
his instruction. For example, the communications teacher and the special-education teacher, who also teaches him language arts, worked together to develop his research project on hockey. He used his computer to find information on the Internet during his language-arts class. He worked with classmates in cooperative work-groups that were designed by the communications teacher and the special-education teacher.

3. Social integration: Ned was quite social throughout the study. The social network that Ned enjoyed at school was large. The strength in Ned’s educational program was found in the strong social network that he enjoyed each day. Many students greeted him in the hallways, initiated interactions with him, and laughed at his jokes in a supportive and reciprocal manner. Ned was difficult to understand. His articulation challenges made some of his communication with adults quite challenging. The students seemed to know what he said, and provided assistance to the teacher when he was in class. He said something to his teacher. She did not understand what he said. The young lady he worked with in the language-arts class intervened saying, “He did not understand your question.”

During the interview with his friends, they indicated that they felt he was treated differently at times and did not need the accommodations that adults provided for him. “He should always be treated like the rest of us.” “Sometimes, he gets treated special and doesn’t need to be, like when he does something wrong. He deserves the same punishment as the rest of us.” Ned’s friends had known him since he started school. Their familiarity with him and acceptance of him were strong. They appreciate him and enjoy his sense of humor. Although he has friends whom he rides the bus with and engages in many social activities at school with typical peers, his closest friendship is
with another student who receives special-education services. Together, they enjoy the many social opportunities offered in their school. I met his friend during one of his classes. Their friendship appeared genuine and reciprocal, and was supported by their typical peers.

4. Transition planning: The advanced planning of major moves was evident in the IEP. The plan for Ned to move to the middle school was developed by his team in advance, and appeared to be implemented in a successful manner. During this study, the principal described her thoughts on his transition to high school. He will be the first student to be fully included at his high school.

5. Community-based training: Ned participated in activities in the community with typical peers. These opportunities occurred in the form of field trips. He did not receive individualized instruction or participate in any community-based instruction on a regular basis. Ned’s spent all of his days in the building with his classmates.

6. Curricular expectations: There was evidence of systematic planning and longitudinal monitoring, based on data that were shared by the para-professional. Ned’s educational program occurred in regular education classes, with the exception of a special reading program which was delivered in a classroom that was taught by a special-education teacher. The class included students with and without identified disabilities. Ned participated in chorus. This was reportedly his favorite class. He sang with the other students and used his sense of humor by gesturing during the songs. The communications class included a presentation by another student who brought her dog to school as part of her presentation. Ned thoroughly enjoyed the opportunity to pet the dog and learn about the many responsibilities that owning a dog involved. He participated in
a child-care class that provided him an opportunity to work with little children. He was very gentle and helpful with the small students who participated in the class.

Reading and Language-Arts instruction provided Ned with opportunities to receive direct instruction from the special-education teacher. He also read out loud, worked in a cooperative group, used his computer to complete a writing assignment, and worked with one girl whom his teacher told me he had a special relationship with.

Ned participated in French class where his teacher took the opportunity to work directly with him during class. She reportedly did this daily while the other students in the class completed individual work. The homework that she reviewed with him was on his computer. Ned appeared to enjoy this class. The last class during Ned's day was a math class. He was tired by the end of the day, and math was his least favorite subject. His math teacher included him in the first aspect of the class, but then he received direct instruction from the para-professional in the classroom. The work he did was individualized. He struggled to stay awake and initiated a variety of topics in an effort to distract the para-professional from the work that needed to be completed. The math teacher was vocal about the fact that he did not do the same work as the other students and would probably be better placed in a different class.

The overall strengths of Ned's educational program included the quality of instruction, in that it was clear that the responsibility of his instruction rested with the classroom teacher, and was supported by the para-professional. The use of assistive technology was evident and effective. The result of regularly scheduled team meetings was evident in the role that the para-professional played. She spent much of her time developing the templates that were used in his computer, and confirming plans with the
classroom teachers. She also helped other students as needed. To me, the curricular expectations were clear.

7. Systematic data-based instruction: Ned's participation and instruction in the regular classes were executed and evaluated by the members of his team in a collaborative fashion. Data were shared by his team, indicating progress towards the IEP goals and objectives. His portfolio was shared with me. In the portfolio, there were samples of his work and frequency data relevant to his tendency to fall asleep. There was no plan to address the sleeping, however! There was clear and useful data relevant to his reading instruction and progress over time. The work samples that were analyzed included assignments from French and Math. The French assignment included pictures and words that he was required to match. His teacher identified what he was responsible for, and his para-professional designed the template on his computer. The math worksheet had pictures of money with corresponding amounts that he was required to match. A second worksheet had a visual display that addressed degrees and angles. Although it was partially completed, it appeared as though this assignment was quite difficult for him. The work samples showed evidence of collaboration and, for the most part, appropriate accommodations for Ned to experience success.

8. Home-school partnership: Ned's parents were crystal clear with their vision and intent to have Ned included in regular education activities. They had frequent communication with his team and enjoyed positive working relationships with them. There were issues shared by the parents during the focus group interview that indicated some challenges that they faced relevant to his math instruction. Based on the observation and a review of his math instruction, their concerns were valid.
Nonetheless, the partnership was strong and effective. The parents’ relationship with the
district administrator was initially negative; however, over the years, it was evident to me
that they had learned to work together and had developed a mutual respect for each other.

9. Systematic program evaluation: The IEP was marked appropriately relevant to
program evaluation. Ned received a report card and had data from his IEP included in
the overall evaluations. There was no formal program-evaluation process in place that
would provide the district with information relevant to the model or strategies used.

Summary

Ned was fully included in his educational program. There was evidence of a
collaborative team process and there was an integrated service delivery model that was
observed and documented. His parents’ strong insistence that he participate in regular
classes was quite evident. He was the first student with mental retardation to be included
in a foreign language class in the middle school. His French teacher was hesitant at first,
but then found him to be a pleasure to work with, but was most impressed with the way
his peers accepted and supported him. He learned to speak some French words and
enjoyed the class. His parents thoroughly enjoyed his success in this class.

Another unique aspect of Ned’s program was the leadership provided to his team
by the principal. She had a presence on the team, and was knowledgeable about every
aspect of his plan. When I asked her about her role, she said that “it was important for
me to be actively involved in his plan because this was new to us and I wanted to be sure
we did it right.”
A Day in the Life of Ned

The following is a story that was written using the data collected relevant to Ned’s educational experience. It is a composition created for the reader to understand some of the highlights that occurred in Ned’s life during this study.

The alarm rang at 6:00 a.m. It flew across the room, landing on the floor, still ringing. Ned was sleeping. The alarm continued to ring until Ned’s dad entered the room, dressed and ready for work. He picked up the alarm, turned it off, and shook Ned until he stirred.

Ned slowly made his way to the bathroom and started to get ready for school. Once he was dressed, he entered the kitchen where his mom and brother were discussing whether or not his brother could drive to school. “I’ll drop Ned off for you,” he said. “I take the bus,” said Ned. “Why would you want to take the bus when you can get a ride?” Ned repeated, “I take the bus.”

The bus arrived on time and Ned boarded. He sat in the first empty seat. The bus arrived at the school just as Ned was starting to fall asleep. He entered the building with all of the other seventh-graders. The students went to home room for their first class. It was at this time that the announcements for the day were shared, and students had an opportunity to make presentations using their closed-circuit video station. On this particular day, Ned had been invited to work the camera with the Communications teacher. Ned is a student in the class that is responsible for announcements this month. He entered the room, greeted the teacher and fellow students, and flung his backpack into
the corner of the room. All peers responded to Ned with typical middle-school sounding
grunts.

Ned approached his teacher enthusiastically. He was carefully instructed on the
video camera’s use. Ned gave it a “test run” for a few minutes. Then it was time to roll.
Together, the teacher and Ned operated the camera. Ned was able to keep it steady on
the first students. He received help when it was time to move the lens to the next student.
Ned operated the camera throughout the broadcast, except when it was time for the
Pledge of Allegiance. He stood with his right hand over his heart and his left hand down
by his side. The camera remained steady. The Communications teacher congratulated
Ned on his superb skill and gave him the next date that it would be his turn to run the
camera again.

As Ned exited the room, Margaret, his facilitator, met him in the hallway and
commented on his nice camera work. As he made his way through the hallways, many
students who knew him said hello or gave him a “high five,” or just merely bumped into
him as a typical means of acknowledging one’s peers in a middle school.

Ned’s first academic class on this day was French. The French class was having a
test. However, the test was somewhat unusual. Each small group within the class
selected a skit. They were instructed to act out the skit in an effort to get their classmates
to say the words, phrases, or sayings in French. Ned’s group included two girls and one
other boy. Their skit involved naming clothing items. The students prepared their skit by
bringing in articles of clothing that they placed on the table and then had their classmates
match the item to the word cards in French. Ned knew the names and pronounced them
with a French accent. As each item was matched correctly to the cards, Ned would say, "Tres bien."

The next class on Ned’s schedule was Social Studies. There was homework due in the class. Margaret met Ned as he entered the classroom. She asked, "Do you have your homework?" He replied, "Some." He sat at his desk and took out the homework that was done. Half was missing. When asked, "Where’s the rest?" he said, "Too tired."

The teacher started instructing the class while Ned set up his computer on his desk. In the computer are his “questions for the day” that he is responsible for in each class. There are also files for each academic area. Ned opened the Social Studies file where he found his vocabulary list for the unit that they were studying. While the teacher was providing instructions to the class, Ned sat at his desk, never giving the teacher eye contact. When the instructions were completed, Ned followed her directions. The students then separated into cooperative-work groups. They had a series of questions that they would answer subsequent to reading and discussing a story. The questions for Ned’s group were entered into his computer by Margaret. Ned sat quietly while the other students discussed the story. Ned read the first question. Another student typed the answers into his computer for him. The group worked for the remainder of the class.

Ned’s next class was PE. This was his favorite class. The boys all gathered at one end of the gym while the teacher laid the equipment out. On this day, the students were going to play floor hockey. When Ned saw the equipment, he quickly made his way to the other end of the gym to assist the teacher. Gradually, all students were gathered around the equipment. The teacher explained the rules and reviewed the safety considerations. He used different students to demonstrate concepts. Ned demonstrated
for the class how to hold the hockey stick. There were several pucks and hockey sticks. The students were instructed to hit the pucks back and forth. Ned actively participated in the game. When one of his classmates noticed how capable he was with the stick, Ned replied, "I play hockey with my brothers. They're good." A variety of games was played, providing Ned the opportunity to be very successful and held in high esteem by his peers.

Ned made his way to the cafeteria for lunch. He found his way to a table where there were six other students. All of the students at the table knew him from elementary school and their neighborhood. Ned greeted them as a group and some responded while others focused on the importance of lunch. Ned got his lunch out and proceeded to eat his sandwich. Some students at the table spoke, but most just ate and made occasional comments. Ned did not offer any comments, but laughed at the appropriate times.

During lunch, tickets for the school dance were on sale. Ned had a five-dollar bill in his pocket and was the first in line. As he approached the teacher with the tickets, the teacher said, "I'm so glad you will be coming to the dance tonight!" Ned responded, "I have a new tie." The ticket was sold, and Ned returned to his seat, only to find that lunch was over and he needed to be at his next class. Ned took the slow route, meeting Margaret as he rounded the corner, who said, "Ned, if you're late, you will pay the consequences. Get moving." Ned laughed saying, "I am, I am!"

Language arts was the next class on Ned's schedule. This class was team taught by a general-education teacher and a special-education teacher. The class included a mix of students with a wide range of abilities. The students in the class were working on research papers. They had to choose a topic of interest and do research on it. Each student would present his or her paper in 2 weeks. Ned was doing a project on the Civil
War. His interest started when his oldest brother, a Civil War buff, took him to a re-enactment. Margaret gave Ned his laptop, saying, “You’d better take this with you. We can download whatever information you need.” Ned took the computer and followed three other students who were heading to the media center to use the Internet for the remainder of the class.

Leaving the media center, Ned headed towards his child-care class. In the hallway, there were several very small preschool students who waited with their mothers for the class to begin. As Ned approached the children, he knelt where a little boy ran up to him saying, “Mommy, look, Ned!” The students entered the classroom where there were several options for young children. The classroom teacher directed Ned to the block area where he was instructed to show two boys how to build a tower. Ned said, “Do this.” The two boys followed Ned’s lead and they proceeded to stack several cardboard bricks on top of each other until they came crashing down. They all laughed and then built a second tower, taller and steadier. The second tower remained while the students headed outdoors for free play and/or a snack. Ned was responsible for bringing the snack items outside for the class to enjoy the warm, sunny day. There were several toys for the students to ride along with balls and sand toys. Ned put the snack items on the picnic table and then picked up a ball, rolling and bouncing it back and forth against the wall. A little girl approached Ned, asking him to tie her shoe. The size of the shoe and laces was a challenging match for Ned’s big hands. He took her hand and walked her over to the teacher saying, “Tie shoes, please.” The teacher tied her shoe and gathered the students for a snack. Ned assisted the teacher in distributing the snacks to the children. He enjoyed the snack with them. By this time, the class was over and it was
time for a new group of students to enter the preschool class to work with the little ones. On his way out the door, the teacher said, “Great job today, Ned.” He smiled and said, “Thanks.”

The last class of the day was math. It was Ned’s least favorite class and he was tired. All of the students entered the room and immediately started to work on the problems on the white board. Ned opened his laptop and proceeded to do the same problems, using his calculator. When the students were ready, the teacher read the problem, the students responded with their answers, and Ned checked their answers with his calculator. He said “That’s right” several times until one student gave an incorrect answer. At that time, Ned made a buzzer noise exclaiming, “wrong.” The students laughed while the teacher said, “Let’s be kind to each other.” Ned then said, “Sorry.”

The class then moved on to some other work while Ned began to work on some individual math problems that were on his laptop. Margaret was in the room, working with Ned on occasion and helping other students as well. Within seconds of walking away from Ned to help a classmate, Ned put his head on the desk and fell asleep. It went unnoticed until the snoring began. The girl next to him snickered and attempted to wake him before the teacher noticed. Too late. Margaret walked over to him and shook him quickly saying, “You have to go to the office for me to get some more pencils. You can get a drink of water on the way back.” Ned hardly moved. Another prompt got him up and moving. He returned to the class with pencils, sliding back into his seat ready to resume his nap. Margaret said, “Ned, if this isn’t finished today, you will have it for homework.” Ned said “OK” and closed his eyes. Margaret reminded him of the dance.
that evening, which was the magic motivator to get him back on task. Ned finished his work, and the class ended.

The students rushed out the door when the day ended, piling onto the buses and heading out of the parking lot within 10 minutes. Once Ned arrived home, he unloaded his backpack onto the kitchen table for his mother to sort out what she needed to read and what needed to return to the backpack. He prepared a snack for himself and then went into the den where he laid on the couch and took the nap that he longed for during math class.

An hour later, Ned woke up, turned on the TV, and watched ESPN, the sports station, for another 20 minutes. By this time, his brother arrived home with friends who entered the room and sat in the chairs facing the TV. Ned's brother commandeered the remote from Ned and began surfing the channels. With that, Ned exited the den and entered the kitchen where his mother was preparing dinner. Ned set the table and assisted in preparing the pasta, meatballs, and salad.

Ned's dad arrived home, just as dinner was ready to be served. Ned's family ate dinner, discussing the day's events and plans for the evening. Ned was excused from doing the dishes that evening so that he could spend the necessary time primping for the dance. Ned selected a white dress shirt, a colorful tie, and dress slacks with a fine leather belt. He completed all aspects of preparation independently with the exception of the tie. His dad stood behind him and stated the various moves that were necessary for the perfect knot. Ned looked dashing and was ready in a timely fashion. His dad drove him and his friend Ronny to the school, instructing him to be at the same location when the dance was over.
Ned entered the gymnasium where there were several students scattered throughout the room, several teachers in various clusters on the sidelines, and a table with refreshments. The school principal noticed Ned and Ronny as they entered the gym. She approached Ned, commenting on his colorful tie. Ned took the end of the tie, flipped it up, waved it in the air, and shuffled sideways onto the dance floor where several students greeted Ned and invited him to dance with them. He danced every dance, taking an occasional break only to get a drink and snack.

When the dance was over, Ned followed his dad’s direction and waited with his friend for their ride. On the way home, Ned fell asleep. His friend was dropped off and Ned was assisted by his dad into the house where he made his way up to bed. He was asleep before his head hit the pillow and the alarm clock remained untouched, as the next day was Saturday!

Themes and Impressions

“It’s my life and it’s my choice,” he told his dad. Ned’s independence and sense of humor were evident before I met him. His mother shared a story of his shopping abilities when he was only 6 years old. While his dad shopped for the items on his list, Ned shopped for items he thought were needed in the house. “Then we looked out in the parking lot, and there he was walking to the car with his basket of groceries!”

From the day Ned was born, the determination and conviction that his parents shared about providing him the same opportunities that were provided for his brothers proved to be a challenge that exceeded their wildest dreams. Ned’s mother was not planning to pursue a degree in law before Ned was born!
Ned’s early learning experiences were always with other children. He had two older brothers who had active roles in encouraging their little brother to be social and funny. His parents learned early on that they were going to have to be crystal clear about how they wanted their son to be educated, that is, included in every aspect of regular-education classes. This was a major paradigm shift for the well-established school district that had provided special-education services in the state before it was required by federal law.

Ned’s parents enrolled him in a preschool that had children in it from his neighborhood. Relationships emerged in Ned’s life from that point on. One of the girls who participated in the interview for friends had known him since preschool. During the focus-group interview, his parents stated, “Everyone knows Ned. He had been in soccer, Cub scouts, baseball and hockey. Everywhere we go, we hear, ‘Hi Ned, Hey Ned’ It’s what we wanted for him. It’s wonderful.” Ned’s social connections were evident throughout the observations and interviews. His popularity and the acceptance that surrounded him daily did not happen suddenly. It also did not happen without reciprocity.

Ned’s educational program was the most collaborative and integrated. The professionals and para-professional responsible for his educational services operated as a collaborative team. The members’ roles were well defined, and the design of his instruction was well organized, appropriate to his level of ability, and integrated with the general-education curriculum.

The theme of satisfaction was shared by most members of his team; however, there were other members of the team who did not experience satisfaction due to a
difference in perceptions about what was an appropriate approach to providing related services. This difference of opinion did not interfere with the overall implementation of Ned's educational services in the general-education setting.

Ned's parents did not share the same level of satisfaction as the other two sets of parents. However, I found Ned's program to be the most inclusive with the most emphasis on learning in the least restrictive environment. This led me to better understand the range of dynamics that existed in each school district, each family, and each student.

During the observations, several social opportunities provided Ned with functional and motivating opportunities to communicate with peers. There were rich interactions in the classrooms with typical peers, both during and after classes. The speech therapist who provided services to Ned in the past, and insisted on serving him in a separate room, might have enjoyed the natural opportunities that this setting naturally lends to address his communication needs. He enjoyed all of his classes, as evidenced by smiles, willingness to participate, and completion of his work. His work samples were evidence of technology, planning, and collaboration. His teachers shared his successes with him, and his classmates enjoyed having him in their cooperative learning groups.

Ned's sense of humor and his creativity were evidenced throughout the study. He had difficulty with articulation, but his communication skills made up for his poor articulation. Ned gestured, used his eyes, pantomimed, and acted out the critical messages he had to convey. He was gentle with the small children, showed respect and concern for his classmates, and never missed an opportunity to take a nap. He fell asleep for a short time in only one class!
The initial codes for Ned's data showed "access to typical peers" and "access to regular education" as the strongest themes, leading to relationships and learning. Although it appeared as though Ned's parents had to fight the hardest for their son's inclusion, he was well integrated and had the strongest theme of learning evident throughout all of his data.

The role of the facilitator was deemed the most successful component of his program. If all children who required significant support in regular-education settings had the likes of this facilitator, inclusion would be more successful. The relationship between Ned and Margaret was the glue that kept his team communicating effectively. It influenced his success over time. Margaret had no formal training; however, she learned "on the job" and became a natural at facilitating in subtle but effective ways. Her time was not spent babysitting for Ned or doing his work for him. She used her time to modify the work as prescribed by his teachers. She always knew where Ned should be, and he had become reliable in getting to where he should be, although his creativity and desire for naps never seemed to leave his mind.

The problem with this is that Ned's educational success seems to have rested largely on the shoulders of the person who is the only one not professionally trained to educate him! I wonder what his educational program would be like without her? It also makes me wonder where the responsibility for Ned's education truly lies.

Relationships, learning, and time together provided this wonderful young man with an educational experience that far exceeded many professionals' expectations.
CHAPTER 7

CROSS-CASE ANALYSIS

Introduction

The purpose of this cross-case analysis is to deepen understanding and explanation and to enhance the relevance or applicability of the findings to other similar settings or transcend "radical particularism" (Firestone & Herriott, 1984). It helps to answer the question "Do these findings make sense beyond this specific case?"

Looking at the complex configurations of the many people, activities, and local dynamics in each student's educational program, a patterning of variables that transcend these three cases emerged in the early stages of this study. Miles and Huberman (1994) developed numerous methods for analyzing data from several cases, leading to categories, themes, or typologies that conceptualize data from all the cases. The analysis showed themes that transcended or cut across all three cases. Analysis also shows the significant differences or uniqueness of each case.

This chapter is organized in the following manner:

The educational teams are discussed in light of their similarities and differences. The educational programs and services are compared in light of their similarities and differences. The students' IEPs and work samples are compared. The locations of the services that the students receive are compared. I then discuss the students' programs using the best practices as a guide.
The Educational Teams

Similarities

The purposeful-sampling procedure that was used for this study put all the boys in middle schools, based on their ages and educational history. Other attributes that met criteria for participation in this study were that both the parents and the boys' support teams considered the boys “fully included.”

The teams included educators from three grade levels: Carl in sixth grade, Ned in seventh grade, and Joe in eighth grade. All three students qualified for special-education services and therefore had a Planning-and-Placement-Team that was responsible for the implementation of their Individualized Educational Plans (IEP).

Table 2 provides the reader with information about the membership of each boy’s team. This provides the reader with a comparison in the number of participants on each team and what roles they played.

Table 2

Membership of Each Student’s Team

<table>
<thead>
<tr>
<th>Participants</th>
<th>Joe</th>
<th>Carl</th>
<th>Ned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal</td>
<td>Indirect</td>
<td>Direct</td>
<td>Indirect</td>
</tr>
<tr>
<td>General Education Teachers</td>
<td>1 (PE)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Special Education Teacher</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Speech Therapist</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Aide</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Parents</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Friends</td>
<td>3</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total Participants</strong></td>
<td><strong>10</strong></td>
<td><strong>12</strong></td>
<td><strong>13</strong></td>
</tr>
</tbody>
</table>
IDEA (1997) requires the participation of general-education teachers in the planning process for all students who receive special-education services. In addition to the general-education teacher(s), each team also included special-education teachers, para-professionals, and the parents. The teams also included other related service providers to varying degrees. Some team members knew the student extremely well and were able to talk knowledgeably about him. Carl was on a team where there were teachers who did not really know him, and thus did not participate in the team interview. Most of the members on Joe's team knew him, but they were lacking involvement from the general academic teachers.

All three teams had some mechanism for communicating with each other and planning for the students' learning activities. In all three situations, adaptations to the curriculum and instructional design were primarily facilitated by special-education personnel. The prevailing practices point to a reliance on special educators to educate students who require specially designed instruction.

All three students spent time in general-education classes. The interview participants seemed to know the students' strengths and abilities in general. Many were eager to share stories with me by responding to all of the questions in great detail.

Each team had a principal who had a presence on the team. The principal was my primary contact subsequent to the parent focus group interview. Each student had a case manager who arranged for the space, time, and interviews. They also informed the teachers that I would be observing and videotaping the students in the classrooms.
There were mechanisms in place for the parents and school personnel to communicate with each other, and there were a variety of informal avenues in place for team members to communicate with each other.

The data from the team interviews were coded according to initial themes. All three teams responded to the first interview question with positive stories about the boys. Stories shared by the team members involved typical peers either supporting the student or providing them with motivation to succeed. For example, Joe was in a general-education PE class. He climbed to the top of a wall and made his way back down with the ongoing cheers of his classmates. Ned was having a difficult time making his way around the track. Just as he was about to give up, his classmates rushed out to the track to encourage him to continue. His classmates gathered around him and finished the race with him. Carl participated in an assembly that provided him the opportunity to be on stage. His music teacher said, “He was treated like and behaved like any other student in the school.”

The successful elements shared by the participants across the three teams included the role of the family or parents as active members of their son’s teams. The other most common response focused on the role that peers played in the boys’ lives. Opportunities for participation in general-education classes were identified, along with individualized or adapted instruction. Each team gave numerous responses that carried the theme of collaboration or team work. The various resources and supports for the boys were identified by each team. The successful elements of the students’ programs shared by the team were categorized into two major themes: relationships and learning.
Relationships

The relationships that existed because of each boy's inclusion in their school cut across many levels. I saw wonderful peer relationships that were engaging, reciprocal, and mutually beneficial to each student. For example, Carl's friends Ben and Sam expressed their appreciation for Carl because "he would say what the rest of us were thinking." Joe's friend said he would not change anything because "Joe is just a great kid."

The relationships in all three cases existed because the parents of the three boys in this study insisted that it be a focus of their education. The team members facilitated the relationships to some degree; however, it was not a primary focus from the perspective of the professional team members.

Mutually beneficial relationships that evolved because of the boys' inclusion in various learning activities were also evident to me. This strong theme extended across all three cases. Each team included people who showed evidence of enjoying each other's stories and sharing their accomplishments relevant to the students' successes.

The barriers that were identified by the teams had some common themes. All three teams said that the students' limitations in their ability to communicate or articulate clearly were a challenge to them. All three teams expressed concern over the boys' abilities to be successful in the regular-education classes. "The curriculum gets more intense and it is harder to break it down for him," stated the special-education teacher for Joe. "Inconsistency. There are days he is responsive and other days he is not," said Margaret, Ned's facilitator. Other barriers identified in common had to do with people's
attitudes. One member of Carl’s team said that some people are “not comfortable” with him. None of the teams identified barriers that would prevent the boys from being included.

When asked what they would change, two of the teams identified a variety of items that would contribute to more efficiency in delivering instruction. Ned’s team was interested in developing his personal management skills more effectively, while Carl’s team wanted more time to plan and work with him. Joe’s team was satisfied to the point where they had no suggestions in response to this question. Thus, the responses were reduced to one theme: satisfaction.

Looking at the future, all three teams saw the boys as continuing their successful experiences as students continuing in middle school or moving on to high school. All three teams saw each boy as successfully employed adults, capable of living in the community with minimal supervision. They all said that they would have friends and a range of interests that would provide the boys with choices and control in their lives. The common theme that emerged from the teams was independence and continued learning. Carl’s parents are adamant about his increased independence. Carl insists on being independent and, therefore, it is a focus in his educational planning process. I do not think that this is the same with Joe’s team. If independence was promoted by Joe’s team, he would be in the special-education settings. Those settings fostered dependence in Joe. Ned’s team encouraged independence throughout his day.

The advice that Joe’s team would offer to others focused on consistency, natural consequences, and opportunities as the most important considerations. Ned’s and Carl’s teams listed many items involving successful strategies and resources. They also
identified "the right attitude" in a variety of ways. Thus, all three teams' advice carried the initial themes around resources, support, and the right attitude.

When the teams had the opportunity to contribute final statements, there was a clear theme of satisfaction and encouragement. "Inclusion is good for the rest of us," said Ned's principal.

Differences

Each team had similarities, but the differences and uniqueness of each situation were most evident to me. The profiles of each team highlighted its uniqueness. The personnel who participated in this study ranged in experience from a fairly new teacher, like Carl's special-education teacher, to the very seasoned educators who made up the team that did not know Carl very well or regard him merely as a member of their classes. The team of people who eventually came together to respond to the interview questions and share their stories about Carl were a positive and energetic group of professionals and para-professionals. Ironically, it was the first time they had come together to talk about Carl. They all knew Carl very well and were able to talk knowledgeably about him. This team did not have any regularly scheduled time to plan for Carl's educational services. The academic teachers met while the students attended the unified-arts classes. The academic team for the sixth grade appeared to "allow" the special-education teacher to attend the meetings, but did not have a collaborative relationship with her. As described in the profile, this team was fragmented, but nonetheless, delivered special-education services to Carl in integrated settings for most of his school day. He spent some time in a
special-education setting that left him alone with an aide for what seemed to be a long period of time.

The work samples for Carl submitted for this study included work from math, computer class, and social studies. All of the work was designed by the special-education teacher. Some of the instructional materials were from the Internet, some were from a work book, and some were teacher-generated. The work addressed Carl's ability level, but was somewhat isolating to him. For example, the work he did in the Social Studies class was completed while the teacher was lecturing to the rest of the class. The teacher did not design the instruction or collaborate with the special-education teacher. The teacher did not evaluate the work either. The grade he gave Carl was based on the recommendation of the special educator.

Joe's team had more in common with Carl's team in that they too did not have regularly scheduled team planning times. The special-education teacher would join an eighth-grade team meeting to get information for planning. She would then meet with Joe's aide and plan his activities with the information she gained. There were no scheduled times with regular education teachers to plan Joe's instruction. Nonetheless, Joe's team expressed a high level of satisfaction. They attributed a great deal of his success to his parents' insistence that Joe participate in general-education classes. They also saw Joe as a very capable young man who was able to learn the appropriate social skills necessary to be successful in the regular classes. Joe was the most integrated student with the label of mental retardation in his school. All of the other students who were considered severely disabled were educated in segregated classrooms. It seemed to me that the students who receive special-education services in this school had to possess
a certain level of social abilities in order to be considered for placement in regular education classes.

Ned's team was the most collaborative and knowledgeable about his educational services. The consistent role of Margaret, his facilitator since kindergarten, was identified by all participants as the most successful aspect of his program. This team was unique because of this. Ned's team was also different from the other two in that this team met weekly to plan for Ned's instruction. There was a defined role for the facilitator to work collaboratively with the teachers in designing instruction. The other aspect of Ned's team that was unique was the role that the educators in the regular education classes played in his instruction. Each teacher was responsible for assessment, instruction, and evaluation of Ned's work. This was not evident or in practice with the other two students. The special-education teachers were the primary designers and evaluators of the other boys' programs. Another significant aspect of Ned's team that separated his from the others was the role that the principal played. This principal had a level of presence and participation on the team that exceeded that of the other two. Although all of the principals were welcoming and had involvement on the teams, the direct participation of Ned's principal, evidenced by her contributions in the interview and presence during the observations, had a measurable impact on the quality of services provided by Ned's team.
The Educational Programs

Similarities

All three boys were observed during a typical school day. They participated in general-education classes and received special-education support services in those environments. Each observation that was conducted started in regular-education classes. Ned's first class was chorus. It was a class that had only boys and they were practicing for a concert. Carl's first class was Language Arts where he filled out a form with some assistance and then enjoyed a video with his classmates. Joe's first class was Foods. He decorated a cake during my observation and worked closely with his peers.

All three boys received the support of a para-professional in the general-education settings. The differences in the delivery of aide services were identified in the previous section. Ned had a facilitator who had worked with him since he was in kindergarten. Carl had aide support, but did not necessarily work with the same aide every day in the same classes. There was a cadre of para-professionals who were assigned to support the special-education students in his school. Carl's parents shared their perspective on this issue. His mother said, "We also do not keep the same aide. He actually has three aides this year. They found that having a one-to-one aide led to problems." This was confirmed by a story shared by Carl's special-education teacher. She said that he was hiding from the aide because she was providing him with too much help. Carl's mother said that "she ended up doing his work!" The aide assigned to Joe had known him for 2 years. Joe's parents shared their view about aide support. His mother said, "We changed every 2 or 3 years. We wanted him to learn to deal with multiple people."
Special-education services delivered by educators were evident in each situation. Although each student had a special-education teacher assigned to him, each had a unique role compared to the other two. Carl’s teacher, for example, designed his instruction based on information she received from the academic team that met regularly. She also provided Carl with direct instruction in math and reading. She did not work with him every day, but provided his aide with work for him to complete and then she worked directly with him on a scheduled basis to monitor his progress. During the observation, Carl spent two consecutive periods in the resource room, a special-education room where students with learning differences receive instruction from either a teacher or an aide. This instruction typically occurred during the times when the regular-education teachers were instructing the non-disabled students in reading and math. During the observation, there were as many as five students in the room at the same time. There was very limited interaction between Carl and the other students during the observation. At one point, Carl and the aide were the only two people in the room (other than the video technician and me).

Joe’s special-education teacher said that she worked with him daily after lunch. She also provided direct instruction to him in reading and math. This instruction was delivered in the special-education classroom where the team interview occurred. She works with him for one period per day. She was also responsible for meeting with the aide each day to plan Joe’s learning activities.

Ned’s special-education teacher instructed him in her classroom, which was his Language Arts and Reading class. This too was considered a special-education classroom, however, there were students served by this teacher who did not qualify for
special-education services, but received instruction from her. Because of this arrangement, Ned received all of his special-education services in integrated settings.

Differences

The Individualized Education Plans

Planning-and-Placement Teams are not required to attach minutes to the IEP; however, each team did attach a summary of the initial planning meeting. All three students had learning goals and objectives in the following areas: Reading and Language Arts, Math, and Communication. Joe's IEP included goals that were clearly the responsibility of special-education personnel. There were no goals or objectives that were specifically designed for delivery in the general-education classes. Carl had some goals that were designed for implementation in the general-education classes. They focused on independence and management of personal materials. Ned's IEP included broad goals and objectives that were applicable in a variety of settings. For example, his reading objectives address his need to scan a selection to locate information. This objective was addressed in every academic class.

Each IEP has a page that summarizes the special-education services, related services, and regular-education hours. During the 2000-20001 school year, Joe was scheduled to receive 18.5 hours of special-education services per week, 3.5 hours of related services (that included speech, adaptive physical education, and counseling), and
10.5 hours of regular-education participation each week. The total number of education hours for Joe was 32.5 hours.

Carl was scheduled to receive 11 hours and 12 minutes of special-education services per week, 2 hours and 5 minutes of related services, including speech and counseling, and 16 hours and 42 minutes of participation in regular-education classes. The total number of education hours for Carl was 30.

Ned’s IEP called for 11.75 special-education hours per week, one hour of related services in the form of PT and OT consultation, and 20.25 hours of participation in regular-education classes. The total number of education hours for Ned was 33.

The most striking difference between the three cases in terms of hours is the fact that Ned’s special-education services are all provided in integrated settings. Joe and Carl receive special-education services in both integrated and separate settings. The initial purpose of stating the hours on the IEP was to identify placement or location of services. This, however, has become more difficult to determine, given the fact that special-education support services can be delivered in the regular-education settings and still be listed as special-education hours. The observations, documents, and clarification with participants allowed me to clearly identify how services are provided to each student. Joe receives the highest number of related-service hours, while Ned receives the least. Joe receives the highest number of special-education hours in a separate setting. That is, he spends more time with other students with disabilities than the other two students. As I stated earlier, Carl also spent time in a separate setting for instruction, while Ned spent no time during his day with students who would be considered disabled.
The most significant difference between Ned’s IEP and the other students was the half hour of team meeting time per week listed on the summary page. Additionally, his learning goals and objectives were global and able to be addressed in a variety of settings. Joe and Carl had IEPs that were written for special-education personnel to implement. The differences in the IEPs played out in the implementation of the plans. That is, Ned’s educational services appeared more collaborative and integrated than Joe’s or Carl’s.

Work Samples

Each of the teams submitted work samples that were representative of their learning activities during the school year. All samples were arranged through the special-education teachers. Carl’s work samples demonstrated his abilities in math, reading, and computers. Ned’s work samples came from French and Math. One of Joe’s work samples was from a Social-Studies class that provided him the opportunity to work in a cooperative group with classmates. All three students in this study received specially designed instruction. Computers played a role in each case, leading me to conclude that assistive technology was available and used with each student.

Location of Services

The most dramatic differences across the cases was in the amount of time that each student spent in a separate or special-education setting. Criteria for participation in this study required that the student “is considered fully included” by the parents and the school teams. The term “full inclusion” became popular after the 1970s and early 1980s.
when some students were selected to be in the *mainstream* of general-education settings. Many students were “dumped” into these settings without the necessary and ongoing supports. The assumption at that time was that special-education services could be delivered only within a special-education classroom. At that time, special education was perceived as a place, not a service. Since the mid-1980s increased numbers of school districts developed inclusive educational service-delivery models. The support services that the student needed were provided in the regular-education settings so that the student was deemed “included.” For this study, I assumed “fully included” meant that the student spent most or all of their time in regular-education settings. I was surprised to learn how much time Carl and Joe spent in special-education settings.

The students’ IEPs specify where the services are delivered, thus separating services delivered in the general-education settings from special-education settings. Joe spent the most time in separate or special-education settings. During the observation, he attended a class that had all students with disabilities enrolled. It was called adaptive physical education. The purpose of such a class was to teach students the skills they needed to participate in general-education PE classes. Given that Joe was successfully participating in a general-education PE class, it was bewildering to me why he was enrolled in this class. The class played a baseball-like game. Joe was the most capable participant in the game. There were aides who supported each student. The class was taught by the PE teacher who participated in the team interview. At the end of the class, I asked one of the aides whether or not the other members of this class participated in regular physical education classes. She responded, “Joe is the only one from this class that is mainstreamed.”
When Joe was observed in the environments where there were only special-education students with significant disabilities, he demonstrated less independence and less self-reliance. This was most evident when Joe participated in a pizza lunch where there were several students with significant learning needs and several aides who were assigned to support the students. Joe spilled his drink and the aides all jumped up to clean up. He was perfectly capable of cleaning it himself. He was also served by the aides, when virtually every student in that class could have served themselves with minimal assistance. It appeared to me as though the path of least effort was taken by the aides in this setting. There were no students or teachers from the general-education setting seen in the special-education classroom, which was located in an area that was not easily accessed by school personnel or typical students. Joe clearly demonstrated more independence and ability when he was with his typical peers in the regular-education classrooms. Given that Joe is considered “fully included,” he seemed to spend a lot of time in segregated settings.

Carl too had several hours for special-education services on his IEP. During his observation, he spent two full class periods in the resource room with an aide working one-to-one with him the entire time. He had demonstrated an ability to remain on task and probably would have been able to complete a great deal of the work that he was doing without direct support. The work he was doing could have been done in a regular-education setting. I suspect that my presence influenced the proximity of the aide to Carl. He did not demonstrate any objection to being in the special-education setting, but he smiled more often and was more socially engaged when he was in the general-education settings with his friends. He yawned a lot in the special-education classroom.
Ned's educational plan identified the least amount of special-education hours. The time that Ned spent in language arts and reading was identified as a special-education setting. The majority of students who were enrolled in that class were students who received special-education services. In addition, there were students in the class who had poor reading skills, but did not qualify for special-education services. Thus, Ned was always in environments where there were students who did not have identified disabilities. Ned remained in the regular-education classes for all other aspects of his day.

Consideration of Best Practices

Williams et al. (1990) identified nine best practices that I used in analyzing the educational services for the three students. In this section, I compare the three cases using the best practices as a guide.

Age-Appropriate Placement in the Public Schools

The placement of choice for all students (regardless of their abilities) should be within their chronologically age-appropriate regular classrooms in the students' public schools. In all three cases, the boys were placed in their neighborhood schools in the age-appropriate grades. None of the three boys spent all of their time in regular education classrooms. Ned spent the most time in regular classrooms, but because he was enrolled in a special-education reading program, he was not always with typical peers. Both Joe and Carl spent a surprising amount of time in separate settings. Educators and other team
members on all three teams seem to believe that there is benefit to separate instruction in separate settings.

Integrated Delivery of Services

The IEPs and instructional programs should indicate the integration of instruction and related services into every possible aspect of their day. This requires a level of communication among the professional personnel who implement the students' IEP.

Joe's educational services were provided in both regular-education classrooms and special-education classrooms. He also received speech services in a separate setting with some collaboration of services in the regular-education classrooms. The members of Joe's team did not have adequate communication to deliver an integrated program.

Carl also received services in both regular-education and special-education settings. The special-education teacher carried a significant amount of responsibility for his instruction. The regular education teachers had no responsibility for his instruction, although the Science teacher and Language Arts teacher both participated in the interview and had positive experiences with him. Carl received speech services in small-group or separate settings. Like Joe's team, his team also lacked adequate mechanisms for communication and planning, which is essential for integrating services successfully.

Ned's educational services were integrated. The team met weekly to plan and integrate his instruction. This was evident across his day. As I described earlier, teachers collaborated in their efforts to address his IEP in different classes. The para-professional spent time developing the modifications directed by the teachers. The most striking
difference across the three cases was the issue of “ownership.” For Ned, the teachers each owned their curricular responsibilities. For Joe and Carl, the instruction rested squarely on the shoulders of the special-education personnel.

Social Integration

The purpose of this practice is to increase the number of environments where social relationships can develop and improve the quality of interactions for the students.

Social opportunities were a strength in each of the educational programs. During the observations, natural greetings and interactions occurred in the hallways. Once in the classrooms with typical peers, social interactions appeared natural and reciprocal. There was no need for facilitation. Joe interacted frequently with his classmates during the Foods class. He worked collaboratively with his classmates to clean up after they decorated their cakes. During the fire drill, Joe’s classmates walked with him to the assigned area, making sure he stayed with the group.

During PE class, Ned’s classmates decided that he would be the first one to pitch the ball for his team. They exchanged frequent “high-fives” and gently slapped each other when their team scored.

During Computer class, Carl worked with his very good friend Ben. Their friendship was brought to my attention by many members of his team. During the observation, Ben was seen with Carl on a number of occasions. His support for Carl was subtle and effective. Ben also participated in the interview with Carl’s friends. When he was asked to share a fun experience, he said, “We have fun every day. I go over to his
Throughout the observation and interviews, it appeared that Ben did not see his friend as a person with a disability.

All three students had friends identified by their parents and team members. In each case, the friends were brought together as a group and asked the same questions. The first group of friends to be interviewed were Joe’s. Their middle school had limited space available. This was the same school where the team interview was scheduled for a room that was seized by a larger group minutes before we were scheduled to begin our interview. Joe’s friend met in a corner of the media center. Ned’s friends and Carl’s friends met in the same conference room where the team had met.

The first two questions asked the students who they were and how long they had known their friend. The most striking similarity across their responses was the number of years that these children have known each other. With the exception of the two boys who had known Joe for only 2 years, through Boy Scouts, all of the other children had known their friend for all of his school years. One of Ned’s friends lived in his neighborhood and had known him for his whole life. Carl’s friends knew him since preschool. I believe the social relationships are a result of the three boys’ parents’ active advocacy.

All of the parents in this study insisted that their sons have social opportunities during the school day. Without the active involvement of the parents, I do not believe that the social relationships would have been as successful.

Each of the children shared stories about their friends. Joe’s friends found his stories about falling asleep to be the most humorous. Everybody who shared stories about Joe, including his parents, talked about his sleeping habits. Carl’s friends said,
“We have fun every day," and Ned’s friends described a game that they played in class 1 day.

When asked if they saw any problems, Carl’s friend Sam was quick to point out that there was an occasion when Carl said what everybody was thinking. The boys laughed saying, “He doesn’t know that you’re not always supposed to say what you are thinking.” We then laugh and say, “Good job Carl!”

One of Joe’s friends said that she intervened one time when she thought Joe was about to be misguided by other students. Ned’s friends shared a similar experience. One friend just intervened by checking with Ned to see if he needed help.

When asked what they would change, the most descriptive response came from one of Joe’s friends. He said, “I don’t really think we should change anything. I mean I think we should work on his listening skills, but other than that, I think Joe is great!”

Ned’s friend said, “Treat him like everyone else.” Another said, “He’s funny, but gets away with acting like he doesn’t understand things and he does.” “I would make sure that everyone knows that Ned has some differences, but that he’s more like us than not.” The themes that emerged in the responses thus far indicate that all three boys had friends who saw them as more like them than different. They all understood that their friend had Down syndrome, but saw little difference in how they related to them as peers.

When asked about high school, all three sets of friends felt that the students would be successful and continue to be supported by teachers and peers. They all saw high school as a big place that would require some adjustment time for everyone.

When I asked what they would tell others about their friend, some of the responses were direct. “I’d tell them he has a disability,” said Carl’s friend Ben. (This is
the friend whom the team members said was a close friend and did not think he saw Carl
as disabled.) Sam said, "I would say, you know, he's funny. He's like us."

"I would say he is missing a chromosome," said one friend. "It's just Down
syndrome." One friend, who had only known Joe from Boy Scouts, said, "I think
people's attitudes change when you get to be around him and see all that he can do. They
don't treat him special. He's one of us."

I gave all of the students the opportunity to share their last thoughts. The
following quotes were made: "I have known Ned since preschool. We have grown up
together. He is my friend. You should get to know him." Carl's friend Sam said, "If
someone tells him to do something wrong, he says, 'Shut up.'" Joe's friends said, "Can
we go get Joe to be on the video with us?" Joe did join the end of the friends' interview.

The strongest theme that emerged from the friends' interviews and observation were
shared experiences that led to satisfaction, social relationships, and learning for all
involved.

Transition Planning

Transition planning should occur well in advance of any major moves. In all
three cases, there was evidence of transition planning among the professionals. As an
eighth-grade student, Joe's team was already in the midst of his transition to high school.
He visited the high school weekly at the end of the school year to familiarize him with
the environment and the regular education classes that he would attend.

Carl was scheduled to also move to a new school for the following school year.
According to his teacher, he had already had an opportunity to visit the next school with
his class. On the day of my observation, he was filling out a form in his Language Arts class that pertained to his move to the next school. His Planning-and-Placement Team was scheduled to meet at the end of the year to design accommodations for his special education services.

Ned was the only student who was not scheduled to move to a new school for the following year. His team was planning his eighth-grade year when the interviews and observations occurred. They had indicated their intention to plan his move to high school early in the next school year. In my opinion, all three cases showed evidence of transition planning.

Community-based Training

The purpose of this practice is to provide the students with opportunities to acquire and demonstrate specific skills within appropriate community settings. Joe participated in some community-based learning activities; however, the activities were scheduled during the school day, requiring him to miss some of the general-education activities. The community-based activities included trips to the local swimming pool where there were only students with disabilities. Other activities included trips to the grocery store to make purchases for a special event that would occur in the special education classroom. Although the intent of community-based activities is to provide the students with experiences that can be useful to them in the future, I found these activities lacked opportunities for Joe to be with and learn from typical peers.

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Carl and Ned did not participate in any community-based instruction, other than the field trips and extracurricular events that occurred with their typical peers. The problem with community-based training is that it is associated only with special education services, and it doesn’t address individual learning needs. It therefore, is not relevant to general-education students. I believe that there is a need for all students to experience the community as learners and should be considered by general educators as an effective means of instruction for students of all abilities. There are some educational programs that now encourage service-learning as examples of a general education curriculum where the community is the basis for learning.

Curricular Expectations

There should be curricula or guidelines that progress from basic or minimal skills to independent functioning in adult life in all areas of instruction. There should also be a system for longitudinal monitoring of the students’ progress. There was no evidence of systematic planning or longitudinal monitoring for Joe or Carl. As stated earlier, both of these cases lacked mechanisms for effective planning and communication among the team members. The development of the curriculum for both boys rested on the shoulders of the special-education personnel. In reviewing the documents and conducting the observations and interviews, my impression was that the curricular planning was somewhat haphazard.

Ned’s team appeared to have a plan that was longitudinal. For example, he was currently enrolled in an introductory French class. The team’s plan was for Ned to take
French during his eighth-grade year, and then continue with French in high school. The Language-Arts instruction included a well-designed plan for improving Ned’s reading skills. He had been receiving instruction using the Wilson Reading Series since sixth grade. Ned was the only student whose team had a plan for data collection over a long period of time. They were able to share data relevant to his reading and math skills that had been used since elementary school.

The curricular expectations and quality of instruction varied greatly across the three cases. Analysis of the IEPs revealed that although the format for developing IEP’s is consistent across the state, each team had a unique strategy for designing and writing learning goals and objectives and implementing the plan.

Systematic Data-based Instruction

There should be written schedules of activities, clearly defined objectives, reliably implemented instructional programs, data-collection procedures, and data analysis. The instructional decisions should be based on documentation of the student’s progress. In Joe’s case, the only data for me to review were the formal assessment data that were in his file. The teacher provided me with samples of his work, but there was no systematic means of assessing his progress as it related to the IEP objectives. There was a daily schedule that Joe followed, with adjustments made as needed. There was no evidence of data being collected for any of the IEP objectives. As stated earlier, there was no mechanism for communication with the regular-education teachers, other than the team meetings that the special-educator joined to gain information before she designed his
lessons. Instructional decisions were in the hands of the special education teacher, even though Joe received the instruction in the regular-education classrooms for some subjects.

Carl’s special-education teacher also had the responsibility for designing his instruction based on information she received by joining the team’s planning times. She did have some data for me to review; however, it was not longitudinal and not necessarily tied to his IEP objectives. Carl had a daily schedule that he kept in his notebook. He had a checklist of his daily responsibilities and was reliable in delivering his completed work to the special-education teacher for her to review and grade. Carl’s and Joe’s teams both lacked a means for designing systematic instruction.

Ned’s teachers met regularly to discuss his weekly instruction. They collaborated in designing his instruction and agreed on what would be used to assess progress over time. This team provided me with data that had been accumulated since sixth grade. Ned’s reading and math instruction was planned and documented specifically around his IEP objectives. The difference between Ned’s team and the others was remarkable. In my opinion, team planning makes all the difference in the quality of instruction.

Home/School Partnerships

The parents who participated in this study were all knowledgeable about the federal laws and their rights as parents of a child with a disability. All three had confrontational or negative experiences early in their sons’ educational careers that put them on notice. Joe’s parents were met with resistance when they attempted to share their vision with the elementary school principal. She was not the principal on the day Joe
started kindergarten. Carl’s parents encountered challenges when they were told that they were responsible for transportation. A meeting with the team resolved that issue. Ned’s parents were challenged by the district when they requested that their son attend a regular preschool. None of the parents in this study found themselves in litigation other than one occasion when Ned’s parents challenged the service-delivery model for related services. The dispute was settled before litigation.

During the focus-group interview, each family shared a favorite story about their son. In all three cases, themes of independence, learning, and social relationships emerged. There was evidence of strong home/school partnerships in all three cases.

Joe’s parents described his program as “good and tight.” A theme of satisfaction was easily coded during analysis. His mother said, “We are dead serious about this,” giving the school personnel a clear message regarding their expectations. They also said “You have to raise people to the greatest expectations.”

Ned’s parents were not happy with some aspects of his educational program. Specifically, they were concerned about his math class. The majority of his program was satisfying to them, which they highlighted. However, both parents expressed hesitation about allowing their son to be educated in a special-education classroom. The most positive aspect of Ned’s program was stated well. “All the kids know Ned. He’s been with the same group of kids for all of the years.”

Carl’s parents described him as “the guinea pig” in the district. He was the first child with mental retardation to be enrolled in regular-education classes. They described their high level of satisfaction and the services he receives during the summer as well.
Joe’s parents said that they had a strong communication with the school. They also described satisfaction with his participation in every social aspect of his educational program. Carl’s parents said, “We feel that the attitudes of the educators and his peers have made a big impact on his success.” In all three cases, learning, relationship, and satisfaction emerged.

All three sets of parents expressed a sense of satisfaction with their sons’ educational programs. Joe’s parents would have liked an adjustment in times of the day for bus pickups or the size of the school. The only change that Ned’s parents would make was his access to extracurricular activities. They felt that he should participate in more social activities and have the support from the school to do that. The theme of satisfaction emerged from this response.

All of the parents had the opportunity to share advice. “Educate yourselves,” they all said. “An educated parent is a teacher’s worst nightmare,” said Carl’s dad. The importance of parent “knowledge” regarding the laws and their sons’ needs was a strong theme. “Finding other parents” was also a theme that emerged as the group responded to the question of advice. The importance of the home/school partnerships emerged throughout this study. Additionally, relationships amongst parents were also an underlying theme that went back to the early days of each boy’s life. Parents got support from each other. The strong relationship between home and school was initiated by each of the parents in these three cases. During this study, it was clear to me that there were students in the special-education classes that I visited whose parents may have lacked the knowledge and partnership that these parents had.
Systematic Program Evaluation

Educational and related services should be evaluated on a regular basis. Such evaluations should involve all program staff and provide administrators with information regarding the achievement of the program goals, student progress, issues requiring remediation, directions for the future, and the impact upon the students, their families, and the community.

In the state where this study was conducted, there are mechanisms in place to evaluate the services of special-education students throughout the state as they relate to the federal mandates. In all three cases, the administrators were able to discuss the role that the state plays in monitoring the implementation of IDEA. None of the team members, including the administrators, were able to identify any local means of systematic evaluation. One administrator said, “I know that when the laws were amended in 1997, the state decided to have us all use new forms for the IEPs to make monitoring easier for them.” Another administrator said, “Program monitoring for the special-education programs is the responsibility of the special-education director. I hear about the results at the board meetings and provide some input, but do not have an active role in the evaluation process.”

Summary

The cross-case analysis compared the three cases using multiple sources of data. There were similarities across the three cases; however, the differences were striking.
Each team had a unique way of communicating (or not communicating) about the
delivery of instruction for each boy. I found the location of educational services to be the
most surprising aspect of the study. Given the criteria for participation in this study,
identified in the section describing the purposive sample, I started collecting data with the
perception that the three boys spent all of their time in regular education settings. I did
not find that to be true. It seems to me that professionals in all three situations continue
to believe that special-education services have to be delivered in separate settings from
typical peers. There was no benefit, in my opinion, to serving any of the boys in separate
settings. As a matter of fact, I found the services for Joe to be detrimental for him. He
acted less capable when he was in the segregated settings. Carl was yawning and
uninterested when he was in the segregated settings. There was nothing in that setting
that led me to believe that it was necessary. Ned was in a special reading class; however,
there were students in the class who were not labeled, therefore, his situation was the
least problematic from my perspective.

Comparing the three cases led me to understand the lack of teacher training in
each of these districts. These three boys are included because their parents insisted on it.
None of the boys are included because it is required by law or considered best practice.
There is a glaring lack of initiative on the part of the professionals to deliver educational
services in integrated settings. The teams in this study all lacked training in how to
deliver educational services in a collaborative and integrated fashion. They all need
training in designing instruction for students with disabilities in regular-education classes.

One underlying theme that emerged through the cross-case analysis is that these
boys are "model students" for inclusion. I could not help but wonder what the
educational services might have looked like if any of the boys had behaviors that interfered with the instruction of other students. Would they be automatically excluded? What if they did not possess the social abilities they had? Would they be excluded?
CHAPTER 8

CONCLUSIONS

Introduction

The purpose of this study was to investigate the educational programs of three boys who were included in their neighborhood schools since preschool. Theoretically, the main issue was for me to sort out some of the indefinite number of influences that contributed to an understanding of three wonderful boys who have taught so many people through their educational experiences. This study provided answers to the following questions:

1. What constitutes a successful program of inclusive education for students in middle school who have Down syndrome?

2. In what ways has their participation influenced others?

Qualitative data were collected from a variety of sources. A focus group interview with the parents of the three boys occurred first. The interview was videotaped and audiotaped. Direct observations were conducted for each student. Each boy's team was interviewed. Each team, along with the parents, selected friends to participate in an interview. All of the interviews and observations were videotaped, transcribed, coded, analyzed, and summarized. There were independent observers who assisted me with reliability, and there were independent coders who validated my findings during analysis.
The parents and administrators provided member checks for the “day in the life” stories. A cross analysis provided the reader with an understanding of the complex configuration of processes within each case. I have “lived” this study for 2 years of my educational and professional career. With that, I have collected a significant amount of data, learned about the lives of these socially and academically competent young men, and offer the following conclusions.

Research Question 1: What Constitutes a Successful Program?

A better understanding of what makes an effective full-inclusion school could be framed within the larger issue: that is, What are the characteristics of a school community that promote beneficial outcomes for all students? A central assumption underlying my study was that the purpose of inclusion is highly relevant to the needs of all children. The essence of this argument is that the development of all children is enhanced by the extent to which they feel a sense of belonging, caring, and community in school.

The Principal

Simply put, an inclusive program cannot be successfully implemented without the support of the building principal. In all three cases studied, the principal played a leadership role for each team. The most extensive inclusion program in this study had the most involved principal. She actively participated in the interview and had knowledge about inclusive practices. Inclusion should not be viewed as an add-on to a conventional
school. Historical analysis has shown that educational impacts are determined largely by the substance of response rather than procedural compliance. For this reason, I believe that inclusion must be embedded deeply within the very foundation of the school, in its mission, its belief system, and its daily activities. It is the principal who sets the tone for that to be a reality.

Resources

Providing resources for the development of the inclusive program is essential. Resources can include materials, books, equipment, technology, and, in some instances, space. Individually, appropriate educational supports and services identified on the students' IEP should be provided to the student in the general-education setting (Meyer, 1998). Many of the supports that students with disabilities require can be provided as part of the instructional arrangements in the general-education classroom. Several years of research suggest that these resources are beneficial for all students, not only those with disabilities (Gambrell, Morrow, Neuman, & Pressley, 1999; McGregor & Vogelsberg, 1998; Tomlinson, 1995).

It Takes a Team

Collaboration and team building are essential. If the truth be known, no one person has the skills to develop and implement an inclusive program, or make one work. Good programs require the combined expertise of general and special educators. It requires leadership from the principal, and the related service personnel who have expertise in addressing the learning needs of the students. Collaboration requires
teachers and other stakeholders to work as a team with a common focus. Research has supported the transdisciplinary and integrated therapy approaches for more than 25 years (Albano, Cox, York, & York, 1981; Dunn, 1991; Effgen, 1995; Giangreco, Edelman, Cloniger & Dennis, 1992; Hart, 1977; Orelove & Sobsey, 1987, 1991, 1996; Patterson et al., 1976; Rainforth & York, 1987; Rainforth & York-Barr, 1997; Sternat, Messina, Neitupski, Lyon, & Brown, 1977; York, Rainforth, & Giangreco, 1990). In this study, Ned had the most collaborative team, received the most integrated services, and demonstrated the most measurable success.

Planning Time

Adequate planning time is essential. Many middle schools now include team planning time, allowing teachers to plan instruction for a common group of students. These teams provide critical input in the design and execution of instruction. Team membership must expand to include special educators and related service personnel who can assist in the planning of instruction, not only for the student with special needs, but also for any student who might require accommodations. Teachers’ and administrators’ time is required to effectively address the complex learning needs of students with intellectual disabilities. The team in this study that met on a regular basis provided Ned with effective instruction, program monitoring, and data that verified his progress. Scheduling time to meet as a team was determined to be one of the greatest challenges faced by the participants in this study. Without planning time, instruction is not well executed and carries less meaning.
A Welcoming Classroom

A welcoming classroom or caring community is necessary for inclusive education programs to be effective. Schools set the stage for students' feelings of self-worth, social responsibility, and belonging, all of which are necessary for developing a compassionate community. Central to the development of a caring community is the promotion of prosocial development (Schaps & Solomon, 1990). The notion of caring is critical in contemporary schools. Students are required to develop skills to learn, to play, to live, and to work with people who are different in a variety of dimensions, including ethnicity, culture, ability, and socioeconomic status (Nevin, 1993). If diversity is valued, students will learn to accept differences as typical. It must be viewed as intrinsic to the mission, philosophy, values, practices, and activities of the school.

Peer Support

A peer support network is critical. In this study, it was the most successful aspect of each student's educational program. Friendships are especially important for various developmental (Guralnick, 1980; Hartup, 1983, Howes, 1983; Rubin, 1982), psychological (Bendt & Perry, 1986; Weiss, 1974) and sociological reasons (Forest & Lusthaus, 1989, Grenot-Scheyer, Coots, & Falvey, 1989; Taylor, Biklen, & Knoll, 1987). Friendships also foster natural supports. An implication of this finding related to empirical research on peer collaboration systems (Villa & Thousand, 1992) is that schools incorporate school-wide peer programs. This means discussing the
importance of peer relationships at the planning meetings, and implementing proven strategies to facilitate peer relationships. One way to accomplish this is to provide opportunities and support for students with disabilities to be included in extracurricular activities. Another approach is for related service personnel to facilitate relationships while delivering services.

Instructional Strategies

Strategies for adapting curriculum and instruction are essential for success. Students with intellectual disabilities are not likely to learn everything that the other students learn. Thus, if inclusion is to be successful, and students with significant differences are to be part of the learning community, there must be a fundamental change in the general-education classroom. It must be recognized not all students will learn the same things in the same way, at the same time. Thus, adaptations of the general-education curriculum are necessary as well as alterations in what is expected of students, how they will receive instruction, and how progress will be evaluated. Vaughn, Bos, and Schumm (2000) take the perspective that much of the work in adapting instruction for a diverse range of learners should be addressed in planning instruction for the entire class.

To make a real difference in the lives of children with disabilities, educators must develop and implement educational methodologies and reforms that ensure that all children can receive a meaningful education in the regular classroom.
Changes in Curriculum

Transformation of the general-education curriculum is necessary. If inclusive classrooms are to include a wide range of students with disabilities as members of their learning and social communities, changes in the general-education curriculum are required. Pugach (1995) has stated that failing to question and change the general-education curriculum results in an “additive” approach to school change, in which the basic assumptions underlying the general-education curriculum are unchallenged. Such assumptions suggest that the current curriculum is acceptable, the special-education teacher is the “adapter,” and practices such as strategy instruction (Schnorr, 1997), class-wide peer tutoring (Mathes, Fuchs, Fuchs, Hanley, & Sanders, 1994), and curriculum-based measurement (Tindal & Marston, 1990) provide an adequate buffer for the dilemmas posed by the standard curriculum paradigm and standard teaching practices. We cannot assume that the curriculum of the general-education classroom remains acceptable.

Professional Development

Professional development must be provided as Fox and Ysseldyke (1997) suggest. It is especially important as teachers are expected to accept different responsibilities and “expand” their roles into new and perhaps personally threatening areas. There was minimal evidence of professional development in the three cases studied. Some training had occurred in each school involved in this study, but none of the districts in this study had a comprehensive training plan addressing the development of an inclusive school community.
Attitudes

Gerben DeJong (1984), in exploring the reasons why persons with disabilities, in general, encounter so many obstacles if not outright rejection, sees the case in the broad general scene. In an article on "Physical Disability and Public Policy," he wrote "The ultimate and most pervasive of environmental barriers are the attitudinal ones. Particularly the view that people with disabilities are helpless, pathetic victims, deserving charitable intervention (p. 8)."

There is now more than enough experience to indicate that disabled people can, with appropriate environmental support, lead full and independent lives. Without the removal of attitudinal barriers, the disability legislation of the past decades will not realize its full potential. To achieve such a basic change in attitude, there need to be changes in public policy on all levels of government, including the legislature, executive, and judicial branches of government. The action also has to come from the person with a disability himself. The mere presence and participation of Joe, Carl, and Ned in their neighborhood middle schools had a positive effect on people's attitudes. Nonetheless, there were still some members of the teams who did not agree with the placement of the student or the service delivery model. In spite of the successful experiences of each boy, some negative attitudes remained, as in the case of Ned's math teacher and speech therapist. All three boys were very well behaved and posed no significant challenges to the teams. I believe that they were accepted because of their social abilities. If any of them had unacceptable behaviors or significant physical disabilities, it would have been much more challenging for the teams. I believe that attitudes may have been different.
Attitudes will not change unless the children themselves are in the general-education classes.

Partnerships

Provision of successful educational programs for students with intellectual differences requires the utmost attention and vigilance by the parents. Not only should the parents know what they want for their child, they should insist on it. Parents should request data to ensure that their child is making progress throughout the year. They should feel comfortable visiting the school and should have access to their child's team when necessary. Parents should be invited to participate in team meetings on a regular basis. Professionals should welcome parent input and consider them as active members of the planning process. It may be that well-educated parents have a greater involvement in school program decisions and an increased likelihood of influencing choices. In this study, all three sets of parents played an active role in their child's educational planning process, thus influencing their educational outcomes.

Organizational Change

Society is gradually moving away from the segregation practices of the past and toward providing all students an equal opportunity to have their educational needs met within the mainstream of general education. A major barrier to this goal, and one that is being recognized increasingly, is continued operation of the dual system of special and

The Michigan State Department of Education Final Report (1993) summarized the positive indications of inclusion with the fact that there appeared to be little, if any, evidence in research to support superior student outcomes as a result of placement in segregated settings. One must seriously question the efficacy of spending ever-increasing sums of money to maintain dual systems, if indeed this is true.

Change in schools is a complex process that calls for interdependence (Rainforth & York-Barr, 1997). Change in one part of an organization affects change in another. For example, curricular changes affect schedules, schedules affect services, and services affect quality of instruction. Organizational change requires action sustained over several years to make it possible both physically and attitudinally for teachers to work naturally together in joint planning, observation of each other's practices, and seeking quality instruction and improvements on a continual basis. Reform does not mean putting into place the latest policy. It means changing the culture of the classrooms, the schools, the districts, the universities, and the government. Schools must develop powerful, usable strategies for powerful organizational change (Fullan, 2001).

**Research Question 2: In What Ways Has Their Participation Influenced Others?**

Many of our books and research in the field of mental retardation have historically focused on what can be done to remediate or alter the limitations of the child
who has intellectual disabilities, when, in fact, those who are not considered intellectually disabled need to learn how to live more compatibly with those who happen to have such labels.

The influence that Joe, Carl, and Ned had on others is dramatic. The themes that emerged through extensive data analysis are the answers to this research question.

Satisfaction

Early analysis of the data included codes with the following descriptors: contentment, professional insight, shared roles, collaboration, communication, and success. In this study, each participant had opportunities to share stories about his or her perceptions and experiences with the three boys. During the focus group interview, all of the parents conveyed a sense of pride and accomplishment as they shared the wonderful stories about their sons.

Triangulation of the data clearly conveys this theme. For example, Joe’s dad shared a story about him introducing himself to others while his peers stood around with their hands in their pockets. Joe’s social abilities bring a strong sense of accomplishment to both of his parents. Joe’s team celebrated their satisfaction by describing his great successes in the general-education settings. His teacher said, “Every day is amazing.” His friend said, “I wouldn’t change anything about Joe, I thinks he’s great!”

Ned’s parents shared their happiness in that “everywhere we go we hear, ‘Hey Ned, Hi Ned.’” They also said, “It is great to have come this far and arrive where we are with a clear understanding and expectations from the school system that this is the way it is going to be.” Ned’s parents were the most insistent parents in the study. Their
insistence paid off. Ned’s team shared their satisfaction during the interviews and in between classes during the observations. During the team interview, one member said that “they had an appreciation for what inclusion can be.” They also found satisfaction in their relationship with Ned’s dad. Their advice to others included the concept to “weave and bob” as a team, and to “take time to enjoy the child.”

Carl’s parents described his educational program and the teachers positively. “The teachers love him and they work well with him.” His team shared many success stories during the interview; however, the most dramatic statement was made by the music teacher who said, “This school has been magic for him, just magic.” The strongest theme of satisfaction in this study came from the boys who have a friendship with Carl and value him for the person he is. “I’d say, you know, he’s funny, he’s just like us.” There are few things more satisfying in a middle-school student’s life than belonging.

Relationships

Early analysis of the parents’ focus interview revealed codes that included the following descriptors: access to peers, social opportunities, friendships, interaction, connections, respond, involvement, interest, and membership. Triangulation and analysis of the data led to strong themes of relationships that transcended all three cases.

Joe’s social abilities paired with access to teachers and peers provided him with many opportunities throughout the day to relate to others. During the observation, the principal went out of her way to connect with Joe by acknowledging his work. His special-education teacher said, “When things pertain to him, he gets it.” The speech therapist said, “He has a wonderful sense of humor.” She also said, “He uses humor or
idioms to connect with people.” Another team member said, “Every day, there’s a story.”

In sharing the successful elements of his program, they said, “He’s been integrated since he was a baby,” leading one to understand his strength in relationships with peers. The observations revealed a highly socialized young man who was motivated to engage with many different people throughout his day. His friends from Boy Scouts gave strength to the theme of relationships, where his friendships with the other students are valued and reciprocal. The strongest piece of data that lends the most credibility to this theme is the video footage of Joe with his friends at the end of their interview. “Can we go get Joe now?” they said. Within minutes, they returned with Joe, smiling, enjoying, and relating.

The theme of relationships for Ned evolved from focus group interview data to the observation data and into the responses his team members shared during their interview. His parents stated that he was popular and well known in the community. At school, he greeted many people as he made his way through the hallways. He also interacted with peers in between classes. The rich interactions that occurred during the observation included Ned petting a dog and working with small children in the unified-arts class. Each interaction observed held its own precious moments that led me to understand Ned’s gentleness and ability to relate to so many. Stories that were shared during the interview included descriptions of how his classmates joined to help him in his final lap around the track or receiving help from a group of friends on the floor at the roller-skating rink. His French teacher said that she was impressed with the manner in which his peers supported him and related to him. Their history together lends credibility to the strong network of relationships that Ned enjoyed daily, not to mention the benefit he brought to the people in his school.
Carl's relationships were discussed by his parents during the focus-group interview. His parents said they never treated him like he was an exceptional child. His dad taught him to work for what he wanted. Carl has worked hard for many things in his life, but he makes relationships seem so easy. Analysis of the observation data indicated a high frequency of connections, peers, friends, interactions, and responses. Carl’s interactions with others appeared positive, genuine, and reciprocal. Carl’s positive relationships at home influenced his social abilities at school in that he was always willing to help others, and was also self-reliant. People liked working with him and enjoyed his humor and gentleness. He had close relationships with the special-education teacher and the music teacher. The strongest theme of relationships during the observations and interviews was found in the genuine friendships Carl has with two boys, Ben and Sam. Their friendship is the essence of inclusion.

Learning

Early analysis of the focus group data revealed codes that included the following descriptions: information, help, knowledge, persistence, vision, insight, and independence. Each of the parents who agreed to participate in this study shared stories and experiences that carried a common theme of learning. When the diagnosis of Down syndrome was confirmed for each of these families, they all responded with ferocious appetites for information. The early intervention services that were provided to the boys in this study included materials, training, and support for the parents. The parents in turn
shared their information with other parents while continuing to increase their base of knowledge as the boys got older.

Joe’s dad said that new parents need to “plug into a network of other parents to learn what they need to know.” He said that information should not be more than a couple of years old. Joe’s mom said, “Do your homework,” indicating that parents should know their rights and know what they want before meeting with people from the school. In providing advice for others, they said that “both of us go to all the meetings. If one of us can’t make it, we reschedule it.” Joe’s mom also made the statement that “a lot of kids are placed in the self-contained class because their parents don’t know any better.”

Ned’s mother became so interested in what she learned as a result of having Ned that she pursued a degree in law. Ned’s parents had more difficulty than the others in this study in securing the services that they expected for their son. As indicated earlier, their son had the most collaborative program and the most evidence of integrated related services. I believe that this is due to the knowledge that Ned’s parents had and to their unequivocal vision that he be included in every aspect of his education. To them, that meant not segregating Ned for any part of his day. The theme of learning was quite evident and very beneficial for all people involved in the boy’s education.

Carl’s mother said, “You can’t advocate for your child unless you know a little bit about the laws.” His dad said, “If you go in with your eyes closed, you get whatever they throw on the table.” Then they both said, “Educate yourselves.” When Carl’s parents were challenged by the school system early on, they realized that they had to stay ahead by knowing what their rights were and knowing what they wanted for Carl.
Joe's educational program was filled with evidence of learning—from his climb up the wall, to his teacher's statement, "You can teach Joey anything!" The paraprofessional described him as "very independent." His PE teacher said that "he has internalized important life skills." The speech teacher said, "Joe is a rule-oriented kid with a good work ethic." Observations confirmed these descriptions. Joe follows directions and operates quite independently throughout his school day. I observed him in a variety of situations where he interacted with peers. Joe was constantly watching his peers. He responded to natural cues in subtle ways. Analysis of the videotapes confirmed his scanning skills and ability to integrate information. The successful components described by Joe’s team included his ability to work with other children and through incorporating communication skills into his learning activities. They also confirmed Joe’s parents’ role in his learning. His teacher said, “His parents have high expectations for all of their children.”

The interview with Joe’s friends confirmed the theme of learning that occurred for the typical children in his life. During the interview, one of Joe's friends shared the following: “When we first started going to Scouts and I first met him, I was new and didn't know what he could do. He does a lot! I think people’s attitudes change when you get to be around him and see all that he can do. They don't treat him special. He is like the rest of us.” Such statements can be considered concrete examples of “learning.”

The theme of learning was evident in every aspect of Ned's data. His school day was filled with multiple opportunities where learning was evident. The codes used in the early analysis included these descriptors: respondent, observation, persistence, and independence. In every class, he showed interest and persistence. He responded to
questions and raised his hand to ask questions. He completed work independently and submitted homework that was completed at home. During the observation, he learned the new rules in a game during PE class. After the class, his teacher said that “he does really well. He’s been with these kids since kindergarten. They all learn together.” During Language Arts, Ned actively participated in the class. “His reading skills had improved significantly since the beginning of the year,” said his teacher.

During the team interview, a story was shared that provided me with insight into Ned’s learning. His parents took him to see an ear-nose-and-throat specialist because of difficulties with his palate. Two specialists were assessing him when one asked him about school saying, “What do you like about school?” Ned said, “I like learning angles in geometry!” His response had them all amazed.

His team learned that teamwork was a successful element of his program, and that “he likes working with other students.” In providing advice to others, one team member said, “Never assume he can’t do something. Let him try.” Learning for this team was stated nicely by the principal: “Strong communication among the adults, including the parents is essential—they are members of the team too.”

Carl’s educational program carried a strong theme of learning for all of his team members in this study. For example, during PE class, the teacher instructed the students on the use of a field hockey stick. The information was new to all of the students. Carl attended to the teacher and then watched his classmates before he decided to participate. Two students slowed the puck down for him to hit it, and from that point on, he was able to play the game.
Effective learning occurred for Carl when he worked with his friends. His computer class included opportunities to work at a computer with his friend assisting him. They laughed, talked, and worked as a team. They accomplished what was expected of them.

The learning theme evolved most vividly when the music teacher said, “Actually, I think we have a lot to learn from Carl, how he thinks, how he sees things, because it is not irrational.” The team also identified cooperative-learning groups as a good strategy for instruction relevant to Carl. One team member also said, “His parents just really know their son and have a good relationship with the school district. His progress has been very smooth all the way through.” One teacher said that Carl was successful because he is “just part of the world and vice versa.”

The learning theme transcended Carl’s friends’ interview. One of his friends said, “I’d say he learns differently, but he’s more normal like us.” The relationships Carl has with his friends are evidence of learning on everybody’s part.

**Implications for Practice and Future Research**

Although the available data on the impact of inclusion are limited for students with and students without disabilities in middle school, my findings encourage further investigations of the outcomes of inclusion in a broad sense. More than four decades have passed in the struggle to gain full educational rights for all. Obviously we need to give thought to more effective strategies. Professional development, organizational change, and partnerships with parents continue to beg further research. More research on team
process and collaboration is also necessary. Most importantly, future research must address the issue of segregation and why it continues to be an accepted practice in public education.

As noted by Ted Kennedy Jr. (1986, p. 6), it is those individuals identified as disabled who constitute the “last bastion of segregation.” If this segregation can be broken down in the public school system and all students educated in the mainstream of general education, we will be well on the way to breaking down segregation in society in general.

Labels and Limited Mental Models

The three boys in this study were labeled “mentally retarded” on the IEPs. Unfortunately, this label leads others to preconceived notions about a students’ abilities. Some of the educational services that were provided to the boys were based on their labels rather than their learning needs.

In the mid-1970s and into the 1980s, whenever anyone asked Burt Blatt what field he was in, he would say “mental retardation.” He was a dean of education at Syracuse University and an internationally renowned special educator, but his self-identified career was in mental retardation. Yet, as the years progressed, he became more and more critical of mental retardation as a concept. Increasingly, he saw it as “unhelpful, an impediment to understanding ability, an invented disease, an untrue and unnecessary story, prejudiced inventions about certain people.” It is not real in the way that blindness or illiteracy are real. Blatt (1987) described the label as abusive. It is
abusive in the sense of its undermining the credibility and authority of those so labeled and of giving their futures over to professional’s discretion. Gunnar Dybwad (1999) wondered why it was necessary to call anyone retarded.

Perhaps it is time to abandon “mental retardation” as a classification, rather than continuing the quest for a more humane or more scientific definition of the term. Mental retardation and its various definitions are, in fact, manifestations of the typological thinking that inevitably creates a simplistic and misleading aggregation of people with very diverse needs and characteristics. There must be alternatives for conceptualizing the needs of the people currently referred to as having mental retardation. It may be helpful to ask ourselves questions about what the abandonment of the term and the definitions associated with it could mean in the lives of individuals and families. We must also ask ourselves what abandoning it as a classification might mean for resource allocation and the provisions of services to people who need them.

We must consider the impact of the deconstruction of mental retardation in terms of need versus stigma. In other words, is the aggregation of people into this diagnosis category truly necessary to meet their needs? Are services in the name of mental retardation justified given the risk of stigma associated with the label? How can we achieve a balance between the needs for assistance and the risk of diminished individuality? These thoughts are critical in thinking about the dismantling of the concept of mental retardation.

In *The Conquest of Mental Retardation*, Blatt (1987) wrote of the importance of Stories: “Every story can enhance life or destroy it. Every story can lift us or
depress us. Stories sustain if not make a person's world. And thus, the story
teller holds a certain power and responsibility” (p. 141).

Time is overdue. The millions of people with developmental disabilities who
have been subsumed under the classification of mental retardation deserve a careful
analysis of its impact on the manner in which they are regarded and treated. A careful
consideration of the feasibility of disassembling the aggregation that mental retardation
has become may enhance our vision of what should be. It is time to see people for their
complexity as citizens with the right to participate in fashioning their own lives. The
debate regarding such labels will continue until people understand that everyone has
differences and that the benefits of labeling children based on their abilities or limitations
remain a questionable practice.
CHAPTER 9

THE REST OF THE STORY

*In qualitative work, the researcher’s background can influence the way in which the situation is described, interpreted, and appraised; hence, knowing who the researcher is and where he or she has come from is not altogether irrelevant.*

—E. W. Eisner

This research journey began when I was 10 years old. My 9-year-old brother, significantly disabled subsequent to encephalitis, stood in the doorway and cried as the remaining five siblings in our family exited the house for a full day of school at 8:00 in the morning. “Why can’t I go to school?” he asked.

I was in fifth grade at that time and was known to ask a lot of questions. I got answers, but some questions begged for different answers. That was about 1966, when *Christmas in Purgatory* (Blatt & Kaplan, 1966) was published. This book title was a fitting metaphor that aptly described what life was like for people we called “mentally retarded.” It included pictures that vividly depicted what institutions were like for the people who lived there. It was difficult for me to believe that human beings were being treated less humanely than animals. After looking at the book for the first time, I remember wondering whether or not it was fact or fiction.

Within 2 years of that expose’ my brother was “placed” in an institution to receive an “education.” He survived that environment for only 10 days. In the fall of 1968, the
telephone rang very early one morning, informing my parents that Steven was dead. He was only 12 years old. When my parents went to the institution to get his body, they were so stricken with grief that they failed to ask adequate questions or pursue any type of investigation. I did learn later in my life that his body was bruised and it appeared as though he had been restrained.

The shock of my brother's death changed the lives of all of us. The seeds were sown. Each of us, in our own way, started acting out our grief and desires to change what seemed to be a gross injustice in life. Some good had to come from the pain and anguish that we all felt. My parents became active with the local ARC. My sister pursued a degree in special education. My older brother entered the field of social work, and my youngest brother found employment working with individuals who had significant behavioral difficulties. Another brother decided that there were enough members of the family addressing social justice issues, so he avoided the field completely and entered the business world. Though our pain was deep, I believed that the people who were institutionalized endured a whole lifetime of pain and injustice, with no avenue to escape. Over time, our pain lessened because we were able to focus our energy in positive directions. People in institutions had no hope as long as they remained in those environments.

Volunteering through the Youth Arc (formerly the Associations for Retarded Citizens) and employment through a state agency gave this bereaving teenager momentum to learn more about the phenomenon of disabilities, specifically "mental retardation." I first became employed at a local camp designed only for people who were considered disabled. My first day on the job included no training or orientation. I found
myself outdoors with a group of nine adults with a variety of differences. I had no idea what I was supposed to do, so I let the adults decide how we would spend our time. I soon learned that they had better ideas than I. Though it was never clearly articulated or a clear vision for me, the drive to engage with anyone who would explore the subject and the drive to share an experience relevant to this issue were the early stepping stones in this long, sometimes very dark journey.

Being scholarly was not preeminent in my planning, as life's circumstances made it clear to me that education paired with employment would be the pillars that led to my career in teaching. An associates degree from the community college with 18 more years as a state employee would have stifled the passionate energy that came out of 3 years in the back wards of the state's institutions. Words cannot adequately describe the horrible conditions that existed for people of all ages who happen to have disabilities and were thought "better cared for" in these facilities. There were day halls that merely contained the children of all ages who resided at one facility. They did not go to school. If the administrators at the institution deemed it appropriate, some children were allowed to participate in activities that were referred to as "functional education classes." Other children never left the unit where they ate, slept, and waited.

It is true that a short visit to the back wards of an institution cannot provide, even for the most astute observer, any clear understanding of the problems, complexities, or outright abuses that occurred in those places. The smells, the locks, the horribly crowded day rooms, and the untrained and wrongly staffed facilities made college life quite attractive to me.
A degree in special-education happened while dormitory and apartment living were financed through my continued state employment. I attended classes by day and worked second shift at two different state facilities while I completed a bachelor's degree. By this time (1976), the laws were passed and it was true that "public schools would now be responsible for educating all children, regardless of their abilities." The timing could not have been better. The state and public school administrators were in a panic as to how education might occur for the population we called "mentally retarded." When it was time to experience the world of teaching as a student-teacher, I asked for a placement with children who were significantly disabled. The professor at the university responded to my request saying, "You don't need a degree in education to work with that population." Apparently, he had not yet learned about PL 94-142. After securing certification and a diploma, this new teacher had a compelling interest in being the first to introduce "school" to the children who had been "too involved to leave the unit." After only 2 years as a teacher in an institution operated by the state, I became disillusioned with the lack of initiative and values that permeated the institutional environments. It seemed to me that the administrators and employees of the institutions were more interested in preserving their employment and the amenities as a state employee than they were in teaching skills to the people they were hired to serve.

A teaching degree and a burning desire to travel and know more led this Easterner to the Midwest to pursue a master's degree in special-education. There were no graduate programs in my home state that addressed the needs of the most significantly disabled population. After investigating a variety of considerations across the country, I was accepted at a university that included people who shared my values and had opportunities...
for me to enroll in the graduate program. Learning from experts in Kansas allowed me to experience life as a student and a teacher with a growing passion for providing quality learning opportunities to our most challenged students.

Good weather, the Pacific Ocean, and social interests drew me further west where teaching students with significant learning differences in a public school became a reality. When I arrived in California, I submitted an application to teach the most significantly challenged students in public education. When I expressed my interest in teaching in a “regular school,” the administration hesitated because all of the students in the district who had the most significant needs were educated in special schools called “developmental centers.” There was a “project” that had just been funded, whereby students with the label of Autism would be placed in a public school building. They offered me the job and I jumped at the opportunity. Still segregated in a classroom, the celebrated victory was being in the same building as typical peers! The concept of integration, paired with litigation at the federal level, gave way to opportunities to mix the students together to see what would happen. The adults wavered. The children never stopped.

I could not believe what I learned from my students! They inspired me far beyond my expectations. I learned that using a “time-out room” was no way to teach positive behaviors. I learned that peers were better educators than teachers. I learned that a team that worked collaboratively could deliver quality services in integrated settings! And, I discovered the power of parent knowledge and leverage. From this experience, I discovered that there was a need for strong leadership to make this a reality in public schools across the country.
A few years later, I returned East, now equipped with regular and special-education certification in three states. A consent decree had just been signed, giving plaintiffs and class members the green light to leave the confines of the state institution. With this opportunity, I played an active role in planning the transitions for people who were institutionalized and then given the opportunity to start living, working, and recreating in their communities. It was so exciting to see how successful all of these people could be, while the employees of the institution continued to voice their concern about such moves. This gave me more than enough energy to continue my education and learn why administrators do what they do. I enrolled in the local university where I had earned my bachelor’s degree. I discovered that not all professors shared my values and that they still did not understand the benefits of integration. I was also surprised to learn that they did not understand what IDEA required us to do in planning for school-age children! I learned more about the problems of organizations, change, and political machinations.

During this same time, independent investigations and a job with a local ARC allowed me to explore employment for people we called “mentally retarded.” Lo and behold, they became gainfully employed, lived in their communities, had a social existence, and enjoyed the freedoms that came with a paycheck. These are the same people who were confined to institutions because professionals believed that they were not “ready” to live in the community!

Degrees, certifications, employment experiences, and a tendency to be passionate about the challenges faced by people we call “mentally retarded” helped to shape my vision and my new goal. I started a business that provided expertise to school systems in
developing and delivering quality educational services to the school's most significantly
disabled students. By the third year of business, I had associates join me. Together we
have helped schools to develop educational programs for students who are considered the
most challenged. We do not work in segregated locations unless the intent is to move
students to their neighborhood schools, where they "belong."

Credibility and time in public education, with the continued desire to act or
produce an effect, which is the definition of power (*Merriam-Webster Dictionary*, 1998),
caused me to pursue a Ph.D. in educational leadership. With that came the requirement
for completing a dissertation. So, what is my wonderment? "Why can't I go to school?"
It only made sense that I should answer that question.

Steven, if you were a child today, you would be able to go to school, and you
would have been fully included!
Dear Parents,

Thank you for agreeing to participate in my research study. I have enclosed some information for you to review prior to our meeting on March 11, 2001 at 1:30 PM. as promised, we will end promptly at 4:30 PM.

The consent form provides you with information about the study and a page to sign if you agree to participate. I will also need your son's signature. You may revoke permission at any point in time.

I will need your permission to review the educational records, observe your son at school, meet with his team, and talk to his classmates. There is a permission form for you to sign (on Sunday) and I will send it to the school.

Please bring a picture of your son to the meeting. It can be a school picture, a family photo, or any one that appeals to you. I will not need to keep it. It is only for the meeting.

At our meeting, I will ask you to name two or three classmates that I can interview at school. They should be students that know your son. I will need their parents permission to talk to them as well.

I have enclosed directions for you. I am very grateful for your time and assistance with this project. If you have any questions, please call me at (860) 345-2532.

Sincerely,

Eileen Luddy
March 28, 2001

Dear Mr.

The purpose of this letter is to seek permission to have access to your school and the professional (and para professional personnel) who provide educational support to

I am a student at Andrews University, Berrien Springs, Michigan. I am a resident of Connecticut and am in the process of completing my Doctoral Dissertation. I have attached information about my study. To date, I have completed the family focus group and am now pursuing the opportunity to observe the students in my study and complete interviews with the Planning and Placement Team that serves

I would like to observe the student for the majority of the school day, meet with the teaching team during scheduled planning time, or at the conclusion of the school day. I realize that this request will impact the teaching teams planning time or scheduled work day, and would be most grateful if arrangements could be made to accommodate me for one day. I will need approximately one hour for the team interview.

In addition to completing a direct observation and meeting with the team, I also need to arrange an opportunity to meet with the students who were identified by the parents. The purpose of this is to learn about the students perceptions of their classmate who has Down syndrome. I will follow your policy regarding permission to speak to them. My interview with the students will take approximately 45 minutes (or I can work within the framework of a class period (during lunch or a special).

I will also need copy of ‘s educational record. I will assume any cost associated with copying his record.
I have enclosed the permission forms signed by the parents along with the names of classmates who know their son and have provided encouragement and support to him.

In summary, I am seeking permission to observe during his school day, meet with the team either during their planning time or at the end of the day, meet with the students named by the parents, either during a non academic time or at a time agreeable to all parties, and finally, analyze the educational records.

I know you are extremely busy and that this request requires your time and attention. I am committed to conducting my research in the most efficient and least intrusive manner. I would appreciate hearing from you either by telephone or email. We will then discuss dates and details for proceeding with my request.

Thank you again for your time and consideration.

Sincerely,

Eileen F. Luddy
APPENDIX B

FOCUS GROUP INSTRUCTIONS
FOCUS GROUP INSTRUCTIONS

Thank you again for taking time out of your busy lives to participate in this study. As you know, this is a Focus Group that has been designed for the purpose of gaining information from parents of Middle School boys who have Down syndrome and have been educated in regular classes for all of their educational years.

It is my understanding that you do not know each other and that your children are students in three different middle schools in different towns in Connecticut. You have all agreed to participate in this study voluntarily. Your presence and opinions are a valuable part of this research study.

This focus group will be observed by an Independent Observer named Cathy. She will not engage in the discussion. She will observe your interactions, help me to monitor the time, and monitor the audio tapes.

Each of you has a folder in front of you with the questions that I am going to ask. Each couple will have up to 10 minutes to respond to each question. You may respond individually to each question, or you may expand on what your spouse has shared.

I am going to ask the questions, but will not engage in any discussion on the topic with you. I may ask you to explain something or expand on your response. You may ask each other questions, make comments or request clarification. Do not hesitate to participate in conversation with each other.

Because this is being recorded by video and audio tape, it is important that only one person at a time speak.

Your responses should not include any person's last name. You may name the town you live in, the school your son attends, but not the names of administrators, teachers, or other personnel. You may refer to people by their title or their first names only.

We will go around the table for each question, starting with the person who has the closest birthday to today. After he or she responds, their spouse will respond and we will proceed by going to the right of each person until the question is completed.

We will take a ten minute break at 3:00 PM.

You may write anything you wish on the pages with each question. They can be notes relevant to your response. They can be thoughts after you have responded, or comments that should be included in our data.

I will give you a couple of minutes to review the questions and find out who is going to be first. You may now ask questions of me before the process begins.
APPENDIX C

FOCUS GROUP QUESTIONS
PARENT FOCUS GROUP QUESTIONS

1. Who are you? Tell us about your family and a favorite story about your son.

2. Describe your child's current educational program. Are you satisfied?

3. What have been the most successful elements of your son's educational experience?

4. What, if any barriers (to learning and participation) have you encountered in your son's educational experience?

5. If you could change any aspect of your child's educational experience, what would that be?

6. As you look to the future, what is your vision for your son?

7. If you could give advice to parents of young children with intellectual disabilities, (about education) what would you tell them?

8. What final statement would you like to make regarding educating children with intellectual disabilities?
TEAM INTERVIEW QUESTIONS

1. Who are you? What role do you play on Carl's team?

2. What is your favorite story about Carl?

3. What are the most successful elements of Carl's program?

4. What, if any barriers to Carl's learning and participation have you encountered?

5. If you could change any aspect of Carl's program would you change?

6. As you look to the future, what do you see for Carl?

7. What advice would you give other educators and team members who will have students with intellectual disabilities in the future?

8. What final statement would you like to make regarding this issue?
APPENDIX E

FRIENDS INTERVIEW QUESTIONS
1. What is your name?

2. How long have you known Ned?

3. What fun experience have you had with Ned?

4. Do you see any problems? What are they?

5. How would you change things?

6. What do you think High School will be like for Ned?

7. If other students ask you about Ned, what would you tell them?

8. Do you have any thoughts about how things have changed since you first met Ned?

9. Is there anything else you would like to share?
OBSERVATION GUIDE

Date:

Student:

Location:

Activity: (details):

Participants:

Conversations (start here...add pages)

(Audio on? yes no Video on? yes no )

Subtle factors:

Behavior of the observer:
Directions for the Video Technician

1. You will be operating a SONY 120 digital recorder.
2. You will meet the student we are recording upon our arrival at the school.
3. The purpose of the video is to capture the activities and interactions of the student during the school day.
4. At the conclusion of each class, I will interact with the teachers and support personnel. Please record those interactions.
5. Please record as much of the student's day as possible.
6. If there is a particular interaction that needs to be recorded, I will signal you.
7. If there is a need to stop recording, I will signal you.
8. Please be aware of the students who do not have permission to be recorded. There are two that I am aware of.
9. If there is a problem with the equipment, please notify me.
10. When recording the interviews, please be sure to record each participant's response.

Thank you for agreeing to assist me in this study!
REFERENCE LIST


The Arc. (1997). Early intervention services for children birth through age 2 enacted by P. L. 105-17 (IDEA 97). Author


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